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THE IMPACT OF HEALTH LITERACY ON RATING OF HEALTHCARE  
EXPERIENCE

BY

Robert William Martin, Jr.

A doctoral project submitted to the faculty of the Medical University of South Carolina  
in partial fulfillment of the requirements for the degree  
Doctor of Health Administration  
in the College of Health Professions

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## **Acknowledgements**

I want to thank my committee members. Your insight, direction and assistance were invaluable to the learning process.

Amita, thank you for supporting me all the way through the journey and encouraging me to the finish line. I never could have done this without you as my sounding board along the way.

Will, your humor and wit were always appreciated for perspective when it seemed like my brain had stalled.

Alice Rachel, your ability to remember to consistently (and kindly) remind me about continuing to move forward (however slowly) was incredible. You always seemed to know when I needed a nudge.

For my Dad, your enthusiasm for this project and my pursuit of a doctorate was infectious. I am truly happy to make you proud.

For my Mom, who I know would have loved the idea of having a “doctor” in the family.

To my son, James... Anything worth doing is worth the challenge to do the job right. Be persistent, and finish what you've started!

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EXPERIENCE

BY

Robert William Martin, Jr.

Approved by:

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Committee Chair *Kit Simpson, DrPH* *Date*

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Committee Member *Walter Jones, PhD* *Date*

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Committee Member *Mary Stefl, PhD* *Date*

## Abstract

The Patient Protection and Affordable Care Act (PPACA) changed the landscape of healthcare in a number of ways. Among these was the inclusion of patient experience ratings in the Value Based Purchasing (VBP) program. With this change, it has become imperative for administrative and clinical leaders to understand the drivers and factors that impact patient experience ratings. One association that has been largely unexplored by researchers is the relationship of health literacy to patient experience. This project, using a dataset from the 2012 Medical Expenditure Panel Survey (MEPS), examined the relationship between health literacy and ratings of patient experience. Using binary logistic regression, the results of the analysis showed those with self-reported low health literacy were 94% less likely to give a passing patient experience score (rating of 9-10) than those with self-reported high health literacy. From these results it is established that health literacy levels do play an important part in patient experience scores. As such, policy, operational and clinical leaders should consider targeting resources to education and improvement of health literacy. Future research should continue to explore the relationship between health literacy and patient experience ratings as well.

## THE IMPACT OF HEALTH LITERACY ON RATING OF HEALTHCARE EXPERIENCE

By

Robert William Martin, Jr.

Chairperson: Kit Simpson, DrPH  
Committee: Walter Jones, PhD  
Mary Stefl, PhD

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## **CHAPTER 1 INTRODUCTION**

### **Background and Need**

The Patient Protection and Affordable Care Act (PPACA) of 2010 changed the landscape of American healthcare in numerous ways. Among them was the elevation of the operational importance of patient experience. Patient experience, also referred to in the literature and in practice sometimes as patient satisfaction, is not a new concept in healthcare. However, prior to the signing of the PPACA, it had never before been a concrete part of the reimbursement formula for hospitals nationwide. By including ratings of patient experience, via the results of the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) survey, in the formula for Medicare's Value-Based Purchasing (VBP) program; the strategic and financial impact of patient experience was forever changed (Farley et al., 2014). Overnight, a necessity was created in every hospital to truly understand what influences the patient experience and how best to improve the scores reported by their patients in this arena. Surveys from the Beryl Institute showed as early as 2011, and again in 2013, that patient experience/satisfaction was among the top three organizational priorities reported by healthcare leaders 70% of the time (Wolf, 2013). "Patient satisfaction scores" went from something touted on billboards and in marketing and advertising campaigns to being top of mind priorities for most hospital management teams (Wolf, 2010; Wolf, 2011). Years after the signing of the PPACA, patient experience measures remain just as relevant to the livelihood of successful healthcare organizations, representing 25% of the VBP reimbursement formula (Centers for Medicare and Medicaid Services, 2017). It is vitally important to understand the underlying drivers of a



positive patient experience. The purpose of this paper is to examine the relationship between the ratings of patient experience and another long-standing health policy initiative: health literacy.

At its core, health literacy is about patient “understanding” of the various components and interactions that make up the complex product referred to as healthcare. The 2001 Institute of Medicine (IOM) report, *Crossing the Quality Chasm*, set several “rules” for healthcare redesign. Among these are two that speak to the idea that health literacy and patient experience are intertwined. Rule three states in part, “Patients should be given the necessary information and opportunity to exercise the degree of control they choose over the decisions that affect them” (Committee on Quality of Health in America, 2001, p. 8). Rule seven states, “The health care system should make information available to patients and their families that allows them to make informed decisions when selecting a health plan, hospital, or clinical practice... This should include information describing the system’s performance on safety, evidence-based practices and patient satisfaction” (Committee on Quality of Health in America, 2001, p. 8). Like patient experience, health literacy has been widely researched and, also like patient experience, improvement of health literacy remains elusive for the system at large.

Health literacy is a topic of importance to the entire health care field, both in policy and practice, because of its almost infinitely wide scope and the consequences to both personal and population health as a result of limited/low health literacy. Nearly 90 million American adults have limited health literacy, meaning that they cannot fully access the benefits offered through the health care system (Nielsen-Bohlman, Panzer, & Kindig, 2004). Nearly 9 out of every 10 American adults have difficulty using the information commonly available in health care facilities (U.S. Department of Health and Human Services, 2010). Health literacy impacts

Americans of all races, income levels, educational backgrounds, and ages (U.S. Department of Health and Human Services, 2006). This epidemic of low health literacy has a tangible negative impact financially as well. Low health literacy has been estimated to cost the economy of the United States anywhere between \$106 billion and \$236 billion annually (Somers & Mahadevan, 2010).

In the Institute of Medicine (IOM) report, *Health Literacy: A Prescription to End Confusion*, it states that health literacy is “a critically important” determinant of health (Nielsen-Bohlman et al., 2004). In a later IOM commissioned paper, Ratzan says that health literacy can be the “most important contributor to health” (Ratzan, 2009, p. 78). Health literacy can be defined as “enabling patients to understand and act in their own interest” (Nielsen-Bohlman et al., 2004, p. xi). The premise is simple. Patients have the right to understand the information that is necessary for them to safely care for themselves (DeWalt et al., 2010). The aim of government policy as it relates to health literacy is founded on the theme of “understanding.” As stated in the 2004 report, *Prevention: A Blueprint for Action*, “The core of the health literacy concept is understanding” (U.S. Department of Health and Human Services, 2004, p. 15).

Health literacy is not just an educational or economic issue. Research studies have shown that there is a strong, independent association between health literacy and health outcomes. These outcomes include mortality, physical health, hospitalization and emergency room utilization (U.S. Department of Health and Human Services, 2006). Low health literacy is associated with reduced use of preventive care services, and poorer management of chronic conditions. It also leads to low rates of treatment compliance, higher rates of hospital readmission, longer hospital stays, higher mortality, medication errors (misuse and omission),

and higher instances of misdiagnosis due to poor communication between providers and patients (Somers & Mahadevan, 2010).

In this paper the numerous aspects, associations, and impacts of both patient experience and health literacy will be discussed as they relate to care delivery, clinical outcomes, and financial performance. Through use of a publicly available national survey data set, an examination of whether there is any significant correlation between improved patient reported understanding (health literacy) and higher ratings of overall healthcare experience will be explored. At the conclusion of this project, it is the hope of the author that the audience will come away from this report with a little better understanding of two mainstays of national health policy, patient experience and health literacy, and how they relate to one another.

### **Problem Statement**

The impact of health literacy on health outcomes and behaviors has been stated and reinforced in the literature numerous times. *However, the literature appears to be lacking with regard to full exploration of the relationship between health literacy and patient experience.* To this end, the purpose of this project is to research the relationship between health literacy and the overall rating of patient healthcare experience. While it might seem intuitive that this relationship exists, a published report from 2013 found no difference on overall ratings of care between patients of differing health literacy levels (Aboumatar, Carson, Beach, Roter, & Cooper, 2013). Patient satisfaction is a commonly measured aspect of performance in healthcare delivery settings today, and understanding the drivers of patient experience is necessary for continued operational and clinical improvement, as well as increased financial performance. For healthcare administrators, knowledge about the impact of health literacy on patient experience can help

clarify where organizational resources (money, training, and time) should be targeted, especially if reported patient experience is not meeting internal goals or external benchmarks. For clinical practitioners, the implications of understanding the importance of health literacy on patient experience could provide the necessary evidence to support process or practice pattern changes, or ignite adoption of different educational or communication strategies between providers and patients.

### **Research Question and Hypothesis**

This project proposes to answer the question, *“Is there a significant predictive relationship between health literacy and overall rating of patient experience?”* This will be accomplished through utilizing publicly available data from AHRQ’s 2012 Medical Expenditure Panel Survey (MEPS). A comparison will be made between health literacy, as represented by two questions, “In the last 12 months, how often did doctors or other health providers explain things in a way that was easy to understand?” and “In the last 12 months, how often were these instructions easy to understand?,” and the overall rating of patient healthcare experience as recorded through responses to the question, “Using any number from 0 to 10, where 0 is the worst health care possible and 10 is the best health care possible, what number would you use to rate all your health care in the last 12 months?” (Agency for Healthcare Research and Quality, 2012b). The hypothesis of this study is that higher ratings of overall patient experience are associated with higher levels of reported understanding for both explanations and instructions. The null hypothesis is that there will be no association (positive or negative) between ratings of healthcare experience and reported understanding of explanations or instructions. The rationale behind the hypothesis is that if a patient understands his/her health better via clear instructions

and better explanations, then that elevated literacy regarding the patient's health should lead to higher ratings of the overall care experience.

## **CHAPTER II REVIEW OF THE LITERATURE**

### **Part 1 - Health Literacy**

#### **Definition**

The National Literacy Act of 1991 defines functional literacy as, “The ability to read, write, speak, and compute and solve problems at levels of proficiency necessary to function on the job and in society, to achieve one’s goals, and to develop one’s knowledge and potential” (U.S. Department of Health and Human Services, 2004, p. 15). The concept of literacy in terms of education, training and normal societal function is not new. In many ways, the ability to read, write, and otherwise communicate is the purpose of primary and secondary education in the United States. However, applying the concept of literacy to the health care field takes on a different, more complex, connotation. Health literacy “refers to a broad set of skills that help patients understand health information, implement basic self-care activities, and navigate health care systems” (DeWalt & McNeill, 2013, p.3). The Patient Protection and Affordable Care Act (PPACA) of 2010 defines health literacy as, “The degree to which an individual has the capacity to obtain, communicate, process, and understand basic health information and services to make appropriate health decisions” (Centers for Disease Control and Prevention, 2016, p, 1). Health literacy is more than reading. It includes writing, numeracy, listening, speaking, and conceptual knowledge of health (Nielsen-Bohlman et al., 2004). To elaborate on that definition, consider that health literacy is not just the ability to process information specific to a single

health topic, but a basic broad capacity for consumers, patients, and providers to communicate on many different types of health situations and issues (U.S. Department of Health and Human Services, 2004). Health literacy incorporates a range of abilities: reading, comprehension and analysis of information; following instructions (both verbal and written), interpreting symbols, charts, and diagrams; deciphering and filtering all these inputs, and ultimately, making an informed health decision. The concept of health literacy extends to the materials, environment, and challenges associated with health promotion, wellness, and prevention of disease (National Institutes of Health, 2013). Or, to put it more simply, health literacy is “enabling patients to understand and act in their own interest” (Nielsen-Bohlman et al., 2004, p. xi).

### **Health Literacy: Prevalence and Cost**

Health literacy is a topic of importance to the entire health care field, both in policy and practice, because of its almost infinitely wide scope and the consequences to both personal and population health as a result of limited/low health literacy. More than one-third of American adults have limited health literacy (Hersh, Salzman, & Snyderman, 2015). Nearly 9 out of every 10 American adults have difficulty using the information commonly available in health care facilities, through media, in retail outlets, and communities at large (U.S. Department of Health and Human Services, 2010). Health literacy impacts Americans of all races, income levels, educational backgrounds, and ages (U.S. Department of Health and Human Services, 2006). Limited health literacy is more prevalent among: the elderly, minorities, medically underserved populations, and those of low socioeconomic status (Health Resources and Services Administration, 2013). The Department of Education’s 2003 National Assessment of Adult Literacy found that only 12% of adults in the United States are sufficiently proficient in health

literacy to understand and use health information correctly. In addition, they found that over a third of American adults would have trouble completing common health-related activities like properly following the instructions of a prescription medication label (U.S. Department of Health and Human Services, 2008). This epidemic of health literacy challenges has a tangible negative impact financially as well. One study found that the average annual cost for a Medicaid enrollee was approximately \$2900, but that annual cost increased to an estimated \$10,700 for patients with limited health literacy (Misra-Hebert & Isaacson, 2012). Low health literacy has been estimated to cost the economy of the United States anywhere between \$106 billion and \$236 billion annually (Somers & Mahadevan, 2010).

### **Policy Background and Operational Implications of Health Literacy**

In the Institute of Medicine (IOM) report, *Health Literacy: A Prescription to End Confusion*, it states that health literacy is “a critically important” determinant of health (Nielsen-Bohlman et al., 2004). In a later IOM commissioned paper, Ratzan says that health literacy can be the “most important contributor to health” (Ratzan, 2009, p. 80). In the 2003 report *Communicating Health: Priorities and Strategies for Progress* the official federal government position states that ensuring health literacy is a “fundamental issue of fairness and basic human rights” (U.S. Department of Health and Human Services, 2003, p. 49-50). The aim of government policy as it relates to health literacy goes back to a central theme, “understanding.” As stated in the 2004 report, *Prevention: A Blueprint for Action*, “The core of the health literacy concept is understanding, and the core of the health literacy problem is the mismatch between the public’s functional health literacy and the complexity of... health care systems and public health services” (U.S. Department of Health and Human Services, 2004, p. 15).

Policy makers, from the President of the United States on down, have taken notice of the impact that health literacy has on basically all aspects of health care delivery and general population wellness. Health literacy was officially recognized and prioritized as a public health initiative with *Healthy People 2010* as a formal objective to “improve health literacy.” The aforementioned *Communicating Health* report put forth a total of 10 “action steps” with a host of sub-objectives, recommended to help tackle the health literacy problem. The “actions” start with developing a national agenda and focus for health literacy (U.S. Department of Health and Human Services, 2003). Action was spurred on and supported by the U.S. Surgeon General at the time as well. In remarks made in September 2003, Dr. Richard Carmona spoke of the three health priorities for the Bush Administration being: public health preparedness; health care disparities; and prevention. Dr. Carmona goes on to say that the common problem impacting the ability to achieve all three priorities is “low health literacy” (Carmona, 2003).

The impact and importance of health literacy on public health initiatives is no less realized today. While health literacy was not a central part of the PPACA, some argue that the law cannot succeed without a redoubling of efforts nationally to address health literacy (Somers & Mahadevan, 2010). The federal plan *Healthy People 2020* keeps health literacy as a stated objective under Health Communication and Health Information Technology, HC/HIT-1 – Improve the health literacy of the population (U.S. Department of Health and Human Services, 2013). The *National Prevention Strategy* includes the strategic direction of “Empowered People.” Within this direction, there is a pledge to action stating that the federal government will “identify and address barriers to the dissemination and use of reliable health information” (National Prevention Council, 2011, p. 23).



In 2010, the national agenda called for back in 2003 was formally crystallized into the *National Action Plan to Improve Health Literacy*. This plan formalizes the pledge from the federal government level to continue the all important work on improving the nation's health literacy. This report recognizes that simply increasing the volume of health information available will not improve health literacy. The fact remains that the advances of medical research, health care technology and health care delivery cannot be fully realized without also addressing health literacy. And, that the issue of health literacy has to be viewed as a systemic problem within every part of American culture. Social, cultural, educational, and public health systems are all negatively impacted by low health literacy (U.S. Department of Health and Human Services, 2006). In the 2010 plan there are two guiding principles. First, everyone has the right to information that helps in making informed health decisions. Second, health services need to be delivered in a way that is understandable and beneficial to health and quality of life. From these two guiding principles they have established a three-fold vision of a society that: provides everyone with access to accurate and actionable health information; delivers patient-centered health services; and promotes good health by supporting lifelong learning (U.S. Department of Health and Human Services, 2010). The report gives seven overarching goals for how health literacy can be positively moved in the U.S. and it states that it will take "everyone working together in a linked and coordinated manner" (U.S. Department of Health and Human Services, 2010, p. 2) to really move the needle for improved population health literacy.

Federal policy initiatives like the *National Action Plan* and *Healthy People 2020* as well as the legislative impacts of the PPACA and the Plain Writing Act of 2010 intend to bring health literacy off the margins of clinical practice and organizational focus. Many researchers and

policy makers believe that a system comprised of health literate organizations and providers can break the current cycle of “crisis care” (Koh et al., 2012). To achieve this goal, some policy makers advocate for a complete rethinking of the healthcare delivery system with transformation to a “Health Literate Care Model.” If adopted, this model would produce a national system-level framework that makes health literacy a cornerstone of organizational cultures interwoven in all aspects of service design and delivery, strategy formation, workforce development and executive decision-making. The “health literacy universal precautions” approach to communication, as espoused by Joint Commission, would be the backbone of the model. Full implementation of such a model could ultimately lead to a less wasteful and more efficient system of care, while greatly enhancing patients’ understanding of, and engagement in, their health related activities (Koh, Brach, Harris, & Parchman, 2013).

In an effort to effectively track the implementation of a prospective Health Literate Care Model; formation, adoption and implementation of specific health literacy related performance measures should accompany the system level commitment to change. Berwick offers a hierarchical framework for change that should serve as a guide for performance measurement: first, the experience of patients; second, the functioning of care units or teams he terms “microsystems”; third, the functioning of healthcare organizations; and fourth, the functioning of the entire health care “environment” or system (Berwick, 2002). Berwick states that the model all aligns back to the patient experience, and that any and all changes undertaken at the “higher” levels of the model should be measured in their effectiveness to impact the patient experience (Berwick, 2002). Regarding health literacy, DeWalt and McNeill (2013) state, “Performance measures play a critical role in a comprehensive effort to improve patient care. They allow health

care professionals to track the implementation of recommended interventions and monitor the resulting effects on care processes and health outcomes” (p. 4). In other words, for the desired changes espoused by years of health literacy national policy to truly take hold, there must be a meaningful and systematic way to measure progress, compliance, and improvement as they relate to impacting the experience of patients. Otherwise the efforts to improve health literacy will be lost in the shuffle amongst all the other regulatory and reporting requirements of the health care system at large.

### **Health Literacy and Clinical Outcomes**

According to former U.S. Surgeon General Dr. Richard Carmona, health literacy can “save lives, save money and improve the well being of millions of Americans” (Carmona, 2003). Studies have shown that there is a strong, independent association between health literacy and health outcomes. These outcomes include mortality, physical health, hospitalization and emergency room utilization (U.S. Department of Health and Human Services, 2006). Low health literacy is associated with reduced use of preventive care services, and poorer management of chronic conditions. It also leads to low rates of treatment compliance, higher rates of hospital readmission, longer hospital stays, higher mortality, medication errors (misuse and omission), and higher instances of misdiagnosis due to poor communication between providers and patients (Somers & Mahadevan, 2010). In 2004, the Agency for Healthcare Research and Quality conducted a systematic literature review on “Literacy and Health Outcomes” and found that the literature demonstrated that there was a strong association between health literacy levels and knowledge and use of health care services for: mammography, cervical cancer screening, and understanding of child diagnosis and medication. The literature

also showed a significant association between inadequate literacy and increased risk of hospitalization. The AHRQ study also found that the literature supported a significant relationship between literacy level and knowledge of health issues related to: HIV, smoking, high blood pressure, asthma, diabetes, and contraception use. In summation, the 2004 AHRQ paper concluded that “low reading skill and poor health are clearly related,” but that the “conclusions about effectiveness of interventions remain less well supported” (Berkman et al., 2004, p. 5). In 2011, an updated review from AHRQ was published. The 2011 review found that differences in health literacy level were “consistently associated” with increased hospitalization, more frequent use of the ER, and lower use of mammography and flu vaccinations. In addition, the study this time showed that lower health literacy led to poorer compliance with medication use, poorer ability to interpret medication labels and health messages, and, among elderly patients, poorer overall health status and higher rates of mortality. Also of note, the updated 2011 study found evidence in the literature that health literacy level potentially mediates disparities between blacks and whites. As with the 2004 results, the 2011 study found again that there was insufficient evidence to draw significant conclusions about literacy interventions (Berkman et al., 2011).

### **Recognition of Low Health Literacy**

The evidence for why health literacy is important for all health care leaders to know and understand is overwhelming. However, the more difficult issue is what to do with that knowledge. The first step is recognition of low health literacy. This is easier said than done. Many patients with limited health literacy will not be forthcoming about their lack of understanding. For them, there is embarrassment and shame in admitting they do not read well

or just do not understand. Because of this fact, physicians, nurses, and other health care workers may never know that a patient is grasping much less than what he/she is being presented (The Joint Commission, 2007). There are some warning signs for health care workers to recognize regarding low health literacy. These include: difficulty filling out medical forms, understanding directions on medication, and sharing the medical history with providers (Health Resources and Services Administration, 2013). Other red flags include: frequently missed appointments, lack of follow through on tests or referrals, non-compliance with medications, and identifying pills by looking at them as opposed to reading the label (DeWalt et al., 2010).

There are several researched and published health literacy screening tools found throughout the literature. *The Health Literacy Tool Shed* (found at the following link: <http://healthliteracy.bu.edu/all>), an online warehouse maintained by Boston University (lead academic sponsor Michael Paasche-Orlow, MD, MA, MPH), has links to 191 unique health literacy screening formats published around the world. Indeed, there are so many that one of the most significant challenges to widespread use in the clinical setting is that there is no consensus as to the “best” approach to health literacy measurement (Altin, Finke, Kautz-Feimuth, & Stock, 2014). One is the Single Item Literacy Screener (SILS). It is designed to help target patients with limited reading ability for health information (Morris, MacLean, Chew & Littenberg, 2006). Another is called the Brief Health Literacy Screen (BHLS), a three question assessment tool meant to be efficient for use in the clinical setting to identify patients with limited health literacy (Sand-Jecklin & Coyle, 2014). A third tool is the Health Literacy Skills Instrument (HLSI). The HLSI comes in both a 25-question and 10-question format and is intended to measure print literacy, listening skills, the ability to locate information (via internet search), and use of

quantitative data (Bann, McCormack, Berkman, & Squiers, 2012). The most established health literacy assessment instruments include the Rapid Estimate of Adult Literacy in Medicine (REALM, REALM-SF), the Newest Vital Sign (NVS), and the Test of Functional Health Literacy Assessment (TOFHLA) (Altin et al., 2014).

However, conducting screening tests of this nature is not necessarily the best way to evaluate patients in a clinical setting, as it could discourage patients from seeking care (Indian Health Service Health Literacy Workgroup, 2009). Health literacy always depends on situational context. Even people with otherwise competent literacy skills can be challenged by medical information regarding a complicated condition or course of care, are not familiar with medical terminology or jargon, or are dealing with the shock and confusion of a serious diagnosis or prognosis. (U.S. Department of Health and Human Services, 2008). In order to try and minimize the negative effects of limited health literacy, it is very important that health care professionals refrain from assuming that the patient understands. Some patients with health literacy challenges do not seem to fit the “typical” profile. For instance, they: could be college graduates, are articulate, hold white collar or even other health care jobs, function well when not under stress, and might look over written materials visually and state they understand (DeWalt et al., 2010). The Joint Commission cautions that even those proficient with reading and numbers might be challenged by illness or injury or feelings of insecurity (The Joint Commission, 2007). Avoiding assumptions regarding the patient’s health literacy is a key in mitigating the potential negative effects of low health literacy.

### **Strategies for Improving Health Literacy**

To achieve optimal health outcomes, patients must have knowledge and understanding of their health status and the corresponding plan of care. Promoting health literacy will help improve health outcomes by improving: spoken communication, written communication, patient empowerment, and support systems (DeWalt et al., 2010). One 2008 study reviewed practice patterns at five separate “public health” primary care practices and found the following five strategies to be effective for helping improve patient literacy. These practices are: a team-based effort to identify health literacy issues, starting with the receptionist and working through all team members; use of standardized communication tools; use of plain language, in-person communication, pictures and simple diagrams, and written educational materials specifically geared towards those of lower literacy; partnering with patients to achieve health status goals; and overall organizational commitment to create an environment where functional health literacy is not assumed (Barrett, Puryear, & Westpheling, 2008). With reference to the practice of standardized communication tools, the use of “Ask Me 3,” Motivational Interviewing,” and “Teach Back” are specifically mentioned. The “Teach Back” and “Ask Me 3” methods are cited numerous times in the literature as effective measures for helping to improve health literacy with individual patients. Another study focusing on the role of health literacy for pharmacist interaction also cites these two processes and it details the process for “Ask Me 3.” This method relies on simplifying the patient encounter by getting the patient to ask, and thus have answers to, the following questions: “What is my main problem? What do I need to do? Why is it important for me to do this?” (Johnson, Moser, and Garwood, 2013, p. 952). Teach Back, another of the frequently cited methods, gets patients to repeat in their own words what they need to know or do. This is done in a non-shaming way and is meant to serve as a check for understanding from the patient regarding the plan of care. If full understanding is not demonstrated, then it provides

the opportunity to re-teach the information before ending the patient encounter (DeWalt et al., 2010). Use of “plain language” is also a frequently recommended measure for improved health literacy. According to the CDC, the primary tenants of plain language are: communicating so your audience understands the first time; cutting out unnecessary words, sentences, and paragraphs; minimizing jargon; and always putting the most important message first in the discussion (Centers for Disease Control and Prevention, 2012).

Maybe the most important strategy that was found in the course of this review is the idea of employing a “universal precautions” approach to health literacy with all patient encounters. This is one of the methods recommended by The Joint Commission, and it employs the use of health literacy training materials and teaching methods geared towards low literacy patients, regardless of patient demographics or history, to help ensure that all patients understand the plan of care (The Joint Commission, 2007). Rather than use a selective screening approach for limited health literacy, a universal precautions approach for confirming patient comprehension of plan of care helps ensure that all patients’ health literacy issues are addressed (Paasche-Orlow, 2011). Universal precautions are also recommended by Dr. Rima Rudd from the Harvard School of Public Health. Dr. Rudd has researched and written extensively in the health literacy sector. By adopting a universal precautions approach to health literacy as a practice or healthcare system, and properly train all staff members on the desired processes, the organization can avoid the pitfall of human “assumptions” about the patient’s understanding (Rudd, 2010).

### **Feasibility and Advisability of Health Literacy Strategies**

Some experts have expressed reservations about routine screening for limited health literacy. The strongest argument they make against routine screening is that the interventions



available are not conclusively proven to boost patient understanding (Powers, Trinh, & Bosworth, 2010). Barry Weiss, MD, a long-time researcher and thought leader on the topic of health literacy espouses, “There is no evidence that routine health literacy assessments in clinical practice result in improved outcomes” (Weiss, 2014, p. 16). As Joanne Schwartzberg and her colleagues state in their 2007 article on page S102, “At present, very little guidance is available to health professionals that link a particular health communication strategy with improved knowledge, understanding, or subsequent outcomes” (Schwartzberg, Cowett, VanGeest, & Wolf, 2007). One of the factors cited in the literature with regularity was the concept of time and increasingly the lack of time that providers now have for each patient encounter. As Powers et al., mention in their article on page 78, “While nearly all physicians agree (with the recommended interventions) they may not effectively adhere to them owing to the time limitations of a busy practice” (Powers et al., 2010). The same study states that the physicians who were informed of the health literacy status of their patients were three times more likely to use the recommended communication strategies to help improve health literacy (Powers et al., 2010). Schwartzberg et al., echo the point about time, listing it as a primary barrier to non-adoption of health literacy practices in the clinical setting. Even though their study showed that providers widely supported and accepted methods such as Teach Back, pictures, and simple language; far fewer providers reported actually using these methods to help improve literacy with their patients. As a result, Schwartzburg and her fellow researchers call for more research specifically in the area of adoption barriers for health literacy measures (Schwartzberg et al., 2007).

It should be noted that in spite of the aforementioned barriers to implementation of health literacy screening, some studies have found it feasible to screen in the clinical setting. One such study tracked the implementation of the BHLS into the nurse intake portion of the electronic medical record used at a large academic hospital system. They found a screening completion rate using that tool of 91.8% for all inpatients over an 18 month span and a 66.6% compliance rate over 12 months for the outpatient clinic setting (Cawthon, Mion, Willens, Roumie, & Kripalani, 2014). Another study conducted at an academic hospital embedded the REALM-SF in the nursing assessment portion of the electronic health record for inpatients. In that study they found an 84% screening completion rate over a 6-month review period (Warring et al., 2018).

The previously cited studies demonstrate that health literacy screening can be accomplished clinically. The question of whether the screening should be implemented clinically is more controversial. One study employed use of the Newest Vital Sign (NVS) as a screening instrument to identify low health literacy with over 2,000 surgical practice patients participating in total. Of the 2,026 eligible for screening, not a single patient refused. These researchers found the NVS took just over two minutes to complete on average, and reported that patient satisfaction ratings actually increased over the two year period of the study (Komenaka et al., 2013). A different study linked increased satisfaction ratings to health literacy screening and use of improved communication tools for impacted patients. It looked at implementation of the Newest Vital Sign into a surgical practice and found that over a span of four years with more than 3000 patients screened, zero patients opted out or refused to complete the health literacy assessment and overall patient satisfaction ratings for the practice in that time increased each year. The authors of this study advocated for the use of health literacy assessment in clinical

practice as a tool for better informing providers which patients might need additional communication and time to fully understand their care, and stated that the NVS in particular only added about two minutes of encounter time to complete the assessment. They also argued that by implementing the health literacy screening; the tools of effective communication could be specifically targeted to the patients requiring the most help (81% of the patients screened had inadequate health literacy) in this area, helping to positively influence patient satisfaction (Eubanks et al., 2017). A smaller and earlier study found that over 98% of patients screened (284 out of 289 total) agreed to a health literacy assessment in the outpatient practice setting, and that there was no difference in patient satisfaction between those screened for health literacy and those in the control group who were not screened (Ryan et al., 2008).

However, others have argued against the use of health literacy screening in the clinical setting, stating that the possibility for shaming or embarrassing the patient exists if screening is routinely used, causing more harm than good. In addition to exposing a potentially alienating truth, and losing the patient's trust in the screening process; the fact that no specific health literacy tool has proven to be completely without error or is considered to be "best" for the clinical setting leads scholars to lean towards the universal precautions approach that is the prevailing direction in most health policy literature (Paasche-Orlow & Wolf, 2007). A 2011 study from University of North Carolina showed that 90% of participants agreed that screening for health literacy in the clinical setting was beneficial for providers and patients were comfortable with the assessments, but 10% of that study sample responded that such testing in the health care setting was not appropriate or desired (Ferguson, Lowman & DeWalt, 2011). While the issue remains unresolved on the best approach (to screen directly or not, and which

tool is the “best”), the literature shows that in spite of the widespread prevalence of inadequate health literacy providers often remain unaware of patient health literacy levels (Powers et al., 2010). The implication of this lack of knowledge being that many patients will struggle to properly interpret or follow prescription directions, written educational materials, or explanations of test results; and the provider in charge of the plan of care will often not detect or act to mitigate these limitations in understanding (Powers et al., 2010). Thus, combating the low-health literacy epidemic successfully will have to be a team effort.

### **The Health Literate Organization: A Mandate for Leaders**

The approach to adoption and implementation of measures and processes that will consistently be successful in attacking the problem of low health literacy must come from the leadership in health care organizations. This is especially important as health literacy improvement is being increasingly viewed as a systems-level challenge that requires coordinated effort across organizational silos and on multiple levels of the institutional hierarchy (Brach, 2017). As with so many worthwhile initiatives though, the underlying premise is simple. Patients have the right to understand the information that is necessary for them to safely care for themselves (DeWalt et al., 2010). And, health care providers have the duty to provide information in plain language and to check that patients have understood the information before ending the encounter (DeWalt et al., 2010). The Joint Commission has made three main recommendations for healthcare leaders with regard to health literacy. They are: to make effective communications an organizational priority to protect the safety of patients; to address the patient’s communication needs across the continuum of care; and to pursue policy changes that will promote improved practitioner-patient communications (The Joint Commission, 2007).

The Institute of Medicine published a list 10 attributes required for a health literate organization in January of 2012. That list states a health literate organization: has leadership that makes health literacy integral to its mission and operations; integrates health literacy into planning, patient safety, and quality improvement; prepares the employees to be health literate; includes populations served in the design of health information and services in general; meets the population needs with a variety of health literacy skills; uses health literacy strategies in patient communication and confirms understanding at all points; provides easy access to and navigation of health information; designs and distributes print media that is easy to comprehend and act on; addresses health literacy as part of care transitions and communications about medications; and communicates clearly what health plans cover and what the patient would have to pay for services rendered (Brach et al., 2012).

The implementation of processes and shift in culture is not an easy task, but to succeed there must be total commitment on the part of management that health literacy, and the activities surrounding it, are an organizational priority. This is a message that must come from the top. One IOM report calls for senior healthcare management to “enhance its efforts to promote, sustain, and advance an environment that supports principles of health literacy” (Parnell, McCulloch, Mieres, and Edwards, 2014, p.1). That same report espouses the need for formally designated executive responsibility to lead the health literacy transformation effort. The authors exclaim, “establishing an Office of Diversity, Inclusion, and Health Literacy is *essential* to operationalize health literacy across an organization and enhance its viability, focus, and sustainability” (Parnell, McCulloch, Mieres, and Edwards, 2014, p.1).

Adopting a culture of competence with regard to health literacy is the ultimate goal that any entity can achieve, should the company commit to seeing the necessary actions through to completion. These actions include a commitment to health literacy as a foundational aspect of physical environment, staff education and patient communication, with the understanding that perfection in this arena is unattainable. However, a health literate organization is constantly striving for improvement (Brach, 2017). There are numerous tools available for adoption and implementation to help guide the health literacy journey. The steps this author recommends follow here.

### **Adopt Health Literacy Identification and Communication Strategies**

For staff education, health literacy training should become a standard part of new staff orientation. A search for sources of training uncovered the “Effective Communication Tools for Healthcare Professionals” online course offered through the Health Resources and Services Administration (HRSA). This course is free of charge, and is accessible from any internet equipped computer at <https://psnet.ahrq.gov/resources/resource/6442/effective-communication-tools-for-healthcare-professionals-addressing-health-literacy-cultural-competency-and-limited-english-proficiency>. The course takes approximately five hours to complete, and provides a broad spectrum review of health literacy issues, cultural competency, and communication techniques, including use of plain language and “Teach Back” (Health Resources and Services Administration, 2007).

In order to help ensure that every patient is approached with a “health literacy” point of view, the recommendation has been made, as was previously discussed in this review, to adopt the “universal precautions” approach espoused throughout the literature, most prominently by the

Joint Commission (The Joint Commission, 2007). Adopting this process would take away the need for an actual screening tool to be added to practice patterns, but it would mean in-depth training on the communication tools to be used during all patient encounters.

To help foster patient engagement and promote and ensure understanding of the plan of care, organizations should commit to use of tools that spawn dialogue from the patients, making communication a two-way affair. The “Ask Me 3” brochure can be found online at:

<https://www.ihs.gov/healthcommunications/health-literacy/ask-me-3> (Indian Health Service, 2017). In addition, a more comprehensive list of “10 Questions You Should Know” sponsored as part of AHRQ’s “Questions are the Answer” campaign is also available. The “10 Questions

You Should Know” brochure is located online at: <http://www.ahrq.gov/patients-consumers/patient-involvement/ask-your-doctor/10questions.html> (Agency for Healthcare Research and Quality, 2012c). The purpose of both is to try and give patients an aid to remind them to ask questions about their care, and to help streamline obtaining the information that is most important to improving, or maintaining, their health.

Coupled with tools that help to foster questions from the patient, the “teach back” method is recommended for use in any clinical encounter. Research has shown that up to 80 percent of medical information and instruction that patients receive is forgotten and almost half of the information retained is inaccurate (Indian Health Service, 2012). One of the more effective ways to close the gap of message receipt and retention for the patient is to utilize the “teach back” method (also known as the “show-me” method or “closing the loop”). “Teach back” is a way to confirm that one has explained to the patient what he/she needs to know in a manner that the patient understands. Patient comprehension is confirmed when he/she explains the information

back to the clinician accurately in his/her own words (Indian Health Service, 2012). It should be noted that this method takes practice on the part of clinical staff members to fully and efficiently implement into regular clinical process. As with any new program, “teach back” might take more time during the encounter initially, especially when working with a patient who must repeat the exercise multiple times before absorbing the information fully. However, studies have shown that once the method is an embedded part of the routine, it does not add significant time to the patient encounter (Indian Health Service, 2012).

### **Complete an Organizational Assessment of Health Literacy Status**

There are numerous tools and toolkits available to help the committed organization make the culture leap to a health literate organization. There are four main tools recommended for review and use in an organizational assessment, should a healthcare organization undertake such an initiative. The first tool that could be used is the *Health Literacy Universal Precautions Toolkit* (2010). This resource provides step-by-step advice for assessing health literacy in the practice setting and includes tools for improving patient interactions for all health literacy levels (DeWalt et al., 2010) and can be found online at:

[http://www.improvingchroniccare.org/downloads/health\\_literacy\\_universal\\_precautions\\_toolkit.pdf](http://www.improvingchroniccare.org/downloads/health_literacy_universal_precautions_toolkit.pdf). The second entry is an update of the first, with slightly different materials and organization.

The *AHRQ Health Literacy Precautions Toolkit, 2<sup>nd</sup> Edition* (2015), can be found online at:

<https://www.ahrq.gov/professionals/quality-patient-safety/quality-resources/tools/literacy-toolkit/healthlittoolkit2.html>. It is composed of a total of 21 separate tools organized under five categories that emphasize patient engagement and participation and mastery of health literate communication techniques, both written and verbal (Brega et al., 2015). Both of the AHRQ



sponsored toolkits mentioned here would help serve as a catalyst for an operational and educational approach to a health literate organization. Two other toolkit options readily and publicly available are the *Enliven Organisational Health Literacy Self-Assessment Resource* from Monash University in Australia (found at <https://www.hqsc.govt.nz/assets/Consumer-Engagement/Resources/Enliven-health-literacy-audit-resource-Mar-2015.pdf>) (Thomacos & Zazryn, 2013) and *Building Health Literate Organizations: A Guidebook to Achieving Organizational Change* from Unity Point Health in Des Moines, Iowa (found at <https://www.unitypoint.org/filesimages/Literacy/Health%20Literacy%20Guidebook.pdf>) (Abrams, Kurtz-Rossi, Riffenburgh & Savage, 2014).

Another tool that would be of great benefit is *The Health Literacy Environment and Activity Packet: First Impressions and a Walking Interview* (2010). This resource focuses on activities designed to help staff members consider the health literacy environment of their workplace with special emphasis on the phone, the web, and a physical walking tour of the facility (Rudd, 2010). It can be found online at: <https://cdn1.sph.harvard.edu/wp-content/uploads/sites/135/2012/09/activitypacket.pdf>. The final guide that could be utilized is *The Health Literacy Environment of Hospitals and Health Centers – Partners for Action: Making Your Healthcare Facility Literacy-Friendly* (2006). This is a much more comprehensive organizational and environmental assessment guide meant to assist health care leaders to view their sites of care specifically through a lens intended to optimize the health literacy environment. It offers an approach for analyzing literacy-related barriers to healthcare access and facility navigation in order to reveal ways to better serve their patients (Rudd & Anderson, 2006). It can be found online at: <https://cdn1.sph.harvard.edu/wp->

[content/uploads/sites/135/2012/09/healthliteracyenvironment.pdf](http://content/uploads/sites/135/2012/09/healthliteracyenvironment.pdf). These last two guides from the Harvard program offer health care leaders a template for instituting a physical environment of care that is health literate.

### **Adopt an Organizational Health Literacy Action Plan**

If an organization pursued health literacy as a bedrock characteristic of its culture, this plan would serve as the overall framework for health literacy related activities undertaken by the company and would help to ensure accountability to the commitment of making the culture progress to a health literate organization. For the purposes of enacting such a plan, there are two tools recommended to help serve as a guide on such an effort. The first tool is a sample health literacy action plan. It is posted by the Department of Health and Human Services, Office of Disease Prevention and Health Promotion. This sample provides a skeleton for the types of issues that should be covered in an organizational action plan, including stating the problem(s) to be addressed and giving detailed examples of possible priorities and action items used to address each organizational challenge. It can be found online at:

<http://www.health.gov/communication/literacy/sampleplan.htm> (U.S. Department of Health and Human Services, 2014). The other tool is a more comprehensive, interactive workbook titled *Making Health Literacy Real: The Beginnings of My Organization's Plan for Action* published by the Centers for Disease Control and Prevention (CDC). This guide is meant to be used as a tool to construct an organizational action plan by completing the exercises and answering the questions throughout. It also makes references back to other tools previously noted, such as the AHRQ toolkit and the 2006 organizational assessment guide from Rudd and Anderson. *Making Health Literacy Real* can be found online at:

<http://www.health.gov/communication/literacy/Making%20HealthLiteracyReal.pdf> (Centers for Disease Control and Prevention, 2010).

### **Start at the Beginning: The Intersection of Health Literacy and Patient Experience**

There have been some indications in the literature of a tie between health literacy and overall patient satisfaction. One study found that respondents with lower literacy levels were less satisfied with their health plans (Shea et al., 2003). A more recent study looked at the factors impacting patient experience in the AARP Medicare Supplement programs. In that study, researchers found that patients with lower health literacy rated their health care experiences lower than others in the study. They also found that seniors with more health problems tended to have lower health literacy than “healthier” seniors in the study (MacLeod et al., 2017).

The most convincing proof of the link is the development and availability of the *CAHPS Item Set for Addressing Health Literacy for Clinician & Group Surveys* (Agency for Healthcare Research and Quality, 2012a) and the *CAHPS Health Literacy Item Set for Hospitals* (Agency for Healthcare Research and Quality, 2015). According to the official AHRQ website (<https://www.ahrq.gov/cahps/surveys-guidance/item-sets/literacy/index.html>), “The CAHPS Health Literacy Item Sets ask about providers’ efforts to foster and improve the health literacy of patients. They are intended to serve as both a measure of whether health care professionals have succeeded in reducing health literacy demands they place on patients, and as a tool for quality improvement” (Agency for Healthcare Research and Quality, 2018, p. 1). The guide for the outpatient survey was developed in 2012 and can be found at:

<https://cahpsdatabase.ahrq.gov/files/CGGuidance/About%20the%20Item%20set%20for%20Addressing%20Health%20Literacy.pdf>. The inpatient guide was published in 2015 and can be

accessed at [https://www.ahrq.gov/sites/default/files/wysiwyg/cahps/surveys-guidance/item-sets/literacy/about\\_the\\_health\\_literacy\\_item\\_set\\_for\\_hospitals\\_911.pdf](https://www.ahrq.gov/sites/default/files/wysiwyg/cahps/surveys-guidance/item-sets/literacy/about_the_health_literacy_item_set_for_hospitals_911.pdf). The healthcare leader or organization that is serious about addressing health literacy and improving the patient experience would be well-served to implement these supplemental Health Literacy related CAHPS surveys in both the inpatient and outpatient settings; as they can be used as a guide to help identify specific areas for process or quality improvement. Examples include: identification of ineffective communication habits (use of medical jargon, talking too fast), implementing “teach back” or some other process to check for plan of care “understanding,” or pinpointing deficiencies in timely communication of necessary medical information like test and lab results (Agency for Healthcare Research and Quality, 2018). The data gathered through these surveys is specific to the patients in that organization, and thus would be beneficial in illuminating where best to apply resources for training, patient follow-up or facility enhancement; not only for better patient experience scores, but also better overall patient outcomes due to improved health literacy about the components and steps of the prescribed care plan.

## **Part 2 – Patient Experience**

### **Context, Background, and Policy Implications**

In a speech given July 25, 2018 at the Commonwealth Club of California, Centers for Medicare and Medicaid (CMS) Administrator Seema Verma gave a clear illustration of the vision that national health policy leaders have for the direction of American healthcare. In this speech Verma states, “As we transition to a system that delivers value to patients, we must start at the basic level of the interaction that a patient experiences when walking into a doctor’s office. We must cater to the needs of the patient, not providers” (Verma, 2018, p.2). She goes on to say,

“We believe that the system must be about the patient and for the patient” (Verma, 2018, p. 3).

Giving further color, Verma includes that CMS is working “to improve the customer experience and help them (patients) make the decisions that are best for them” (Verma, 2018, p. 3).

Although she does not use the exact terminology, Verma places front and center the fact that patient experience remains a central concern of national health policy leaders.

Patient experience really came into focus nationally with the 2001 Institute of Medicine (IOM) report *Crossing the Quality Chasm*. The report stated that “the U.S. healthcare system does not provide consistent, high quality medical care to all people” (Committee on Quality of Health Care in America, 2001, p. 1). The IOM goes on to delineate six aims for transformative improvement of the healthcare system, stating that all care delivery should be: safe, effective, patient-centered, timely, efficient, and equitable (Farley et al., 2014). Patient experience is a measure of patient-centered care (Browne, Roseman, Shaller, & Edgman-Levitan, 2010).

Donald Berwick, one of the architects of the IOM report, went on to write separately that, “Patients’ experiences should be the fundamental source of the definition of quality” (Berwick, 2002, p. 80). Berwick offered a hierarchical framework for change: first, the experience of patients; second, the functioning of care units or teams he terms “microsystems”; third, the functioning of healthcare organizations; and fourth, the functioning of the entire health care “environment” or system (Berwick, 2002). Berwick states that all improvement aligns back to the patient experience, and that any and all changes undertaken at the “higher” levels of the model should be measured in their effectiveness to impact the patient experience (Berwick, 2002).

Starting in 2002, the Agency for Healthcare Research and Quality (AHRQ) began the process of developing the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) survey. The purpose of this new survey was a standardized tool for measurement of patient experience. After a multiyear review process, the HCAHPS survey was formally implemented by CMS in October 2006, with the first public reporting of survey results in March 2008. Participation in the survey at the beginning was voluntary. As a carrot to boost participation, the Deficit Reduction Act of 2005 authorized a financial incentive for hospitals to participate in the HCAHPS program. Called “pay for reporting,” this system kicked in starting in 2007, and that year nearly 95% of eligible hospitals participated (Siegrist, 2013).

In 2008, the landmark concept of the “Triple Aim” of healthcare entered the national consciousness. Berwick, Nolan, and Whittington stated, “The United States will not achieve high value health care unless improvement initiatives pursue a broader system of linked goals. We call these goals the “Triple Aim”: improving the individual experience of care; improving the health of populations; and reducing per capita costs of care for populations” (Berwick, Nolan & Whittington, 2008, p. 760). The Institute for Healthcare Improvement (IHI) is among the many groups to more closely examine and support the Triple Aim as a staple of national health policy. IHI states the following with regard to measuring the patient experience, “two perspectives are considered: first, the perspective of the individual as he or she interacts with the health care system (i.e., patient experience surveys) and second, the perspective of the health care system focused on designing a high-quality experience for patients as defined by the IOM’s six aims for improvement” (Stiefel & Nolan, 2012, p. 5). IHI goes on to state that the experience of care is best reported by patients who are subject to the care. IHI advocates for use of all six

IOM aims to be included as contributing factors of the overall care experience, stating that all six dimensions are “drivers” of the patient experience and that individual measures for each of the six IOM elements will help provide a complete picture of the care experience (Stiefel & Nolan, 2012).

The work started with the 2001 IOM report and expanded by the Triple Aim was cemented and amplified with the passage of the Patient Protection and Affordable Care Act (PPACA) in March 2010. The PPACA called for numerous changes to the way healthcare is paid for, delivered and consumed. One of the most notable requirements of the law was the inclusion of patient experience ratings, as measured through the HCAHPS instrument, to be included in the financial reimbursement of total Medicare dollars to participating hospitals as part of the Value-Based Purchasing (VBP) program (Farley et al., 2014). Bringing patient experience scores into the financial formula for hospitals nationwide was a game-changer for the way healthcare organizations approached customer service, patient satisfaction, and specifically the results reported on the HCAHPS surveys. For fiscal year 2018 - 2020, there are four VBP domains, each weighted as 25% of the formula. For the “patient and caregiver-centered experience of care/care coordination” domain, the score is determined exclusively by performance on the HCAHPS surveys. CMS is renaming the domain to “person and community engagement” starting in 2019, but the use of HCAHPS scores to determine performance on the domain will remain. The VBP program withholds 2% of total Medicare payments to the hospitals each year, and rates the hospital’s performance on the four domains to determine whether the hospital will be penalized all or part of the 2% or receive additional “bonus” payments for exceeding peer performance. At present and for the foreseeable future, patient

experience scores are now directly connected to 0.5% of a hospital's Medicare dollars annually (Centers for Medicare and Medicaid Services, 2017).

### **Key Definitions and Concepts**

There are a multitude of definitions and concepts that appear in the literature with regard to the idea that has evolved over the years into "patient experience." The Beryl Institute defines patient experience as, "The sum of all interactions, shaped by an organization's culture, that influence patient perceptions, across the continuum of care" (Wolf, Niederhauser, Marshburn, & LaVela, 2014, p. 8). Deloitte's Health Sciences Practice emphasizes the idea of a continual relationship being part of the definition. It states that the patient experience "refers to the quality and value of all interactions – direct and indirect, clinical and non-clinical – spanning the entire duration of care delivery" (Abrams, Laughlin, Shtulberg, and Park, 2015, p. 4). Another definition of patient experience limits the concept of time involved, defining patient experience as follows, "The patient's perceptions of the personal and virtual interactions, clinical interventions and physical environment associated with a given clinical episode, encompassing the time immediately before, during, and after delivery of care" (Sweeney, Nicoloff, & Wagner, 2010, p. 4). Price and her co-authors anchor the definition to what the patient can tangibly observe, stating that the experience is, "Any process observable by patients including subjective (pain was controlled), objective (waited for more than 15 minutes past the appointment time), and observations of physician, nurse, or staff behavior (doctor provided all relevant information)" (Price et al., 2014, p. 526). Irwin Press gives a more expansive definition of the experience concept, and includes the aspect of intention, "Every vista, sound, interaction, and intervention contributes to the overall experience and is interpreted as a purposeful aspect of



care” (Press, 2006, p. 3). Luxford and Sutton emphasize the impact of purpose and control to the patient experience as well, asserting, “Measured or not, patients have experiences at each touch point across the continuum. Unplanned, unmanaged and unmeasured experiences result in low satisfaction” (Luxford & Sutton, 2014, p. 24). The Agency for Healthcare Research and Quality offers the most extensive viewpoint, stating that patient experience “encompasses the range of interactions that patients have with the health care system, including their health plans, and from doctors, nurses, hospital staff, physician practices, and other health care facilities... patient experience includes several aspects of health care delivery that patients value highly such as getting timely appointments, easy access to information, and good communication with healthcare providers” (Agency for Healthcare Research and Quality, 2017, p. 1).

It should be noted that in practice the terms patient experience and patient satisfaction are often used interchangeably, but in concept there are some differences. AHRQ frames patient satisfaction as “whether the patient’s expectations about a health encounter were met” (Agency for Healthcare Research and Quality, 2017, p. 1). However, to assess patient experience, “one must find out whether something that should happen... actually happened or how often it happened” (Agency for Healthcare Research and Quality, 2017, p. 1). Wolf distinguishes between the concepts as a function of time. He argues, “Satisfaction captures perceptions at points in time” (Wolf, 2017a, p. 7). But, “experience is the lasting story consumers carry with them” (Wolf, 2017a, p. 7). In truth, every encounter with the health care system produces a “patient experience.” An experience exists regardless of whether the patient is “satisfied” with the encounter. Irwin Press frames it this way, defining patient satisfaction as the term used for how experience is rated, “Patients’ experiences of care are measured as patient satisfaction”

(Press, 2006, p. 5). Application of the Press explanation of patient satisfaction makes the terms inextricably linked such that referring to “patient satisfaction” in operational practice means to speak of the “patient experience.”

Over time, the theories around patient experience have continued to evolve, broaden, and deepen. In a 2016 publication, Jason Wolf espoused that patient experience “encompasses quality, safety and service moments, is impacted by cost and the implications of accessibility and affordability, is influenced by the health of communities and populations and by both private and public health decisions” (Wolf, 2016, p. 1-2). In addition to the move towards a more “comprehensive” view of what defines the patient experience, there is a growing understanding that patients’ impressions are representations of multiple factors together. In its 2015 report, the Beryl Institute explains, “experience itself is an integration of quality, safety and service as well as outcomes and cost... From the patient and family perspective they do not distinguish quality, safety or service in the way those operating in the dynamic and chaotic healthcare environment do” (Wolf, 2015, p. 9). As an example of continued concept maturation, a 2017 survey found that patients overwhelmingly acknowledged and supported both employee engagement and patient/family engagement as significant defining elements of patient experience, in addition to quality, safety, and service (Wolf, 2017c). Another 2016 study coined the term “interpersonal care experience (ICE)” representing the idea that ratings of care are dependent, not on distinct interactions or remembrances of encounters with a specific doctor, nurse, procedure or treatment, but rather that patients perceive all of these encounters together as a singular aspect of the care experience (Silvera and Clark, 2016). Viewing this concept a little differently, Wolf compares the patient experience to a “patchwork.” He exclaims, “as the breadth of what experience

encompasses expands, it is important to understand that the parts we have traditionally seen as not related in healthcare are critically interwoven” (Wolf, 2017b, p. 2). He goes on to state, “while each individual part has its own role and maintains its distinction, when woven together they become collectively functional in ways they might never otherwise achieve” (Wolf, 2017b, p. 2). While the system overall is greater than the sum of its parts, the important point here is that the patient is viewing all of the disparate parts together in forming one perception of experience. Or, to boil it back down to its roots, experience is “all that is understood, perceived and remembered” (Wolf, 2017a, p. 6).

### **Patient Experience: Challenges of Comprehension and Advancement**

A broad catch-all approach to defining patient experience might be academically accurate and appropriate. A standardized applied operational definition is more elusive. As Adrienne Boissy, MD, Chief Experience Officer at Cleveland clinic states, “If you asked every patient what the patient experience means to them, they would say something different, just as if you were to ask clinicians, they would say something different” (Thew, 2016, p. 13). The operational difficulty presented due to lack of simplicity with defining patient experience aside, it is imperative that health service providers figure out what drives the perception and rating of experience. A recent survey revealed 6 in every 10 patients identify patient experience as “extremely important” to them “as they (the patients) defined it (experience)” (Wolf, 2018b, p. 2). Dr. Boissy’s statement on the uniqueness of perceived experience from one person to the next, or between service providers and patients, is noteworthy; as it alludes to the complexity and challenge for health care leaders in fully understanding, and executing, successful and sustainable plans for achieving high patient experience ratings.

Max Van Manen is quoted as saying, “Serious illness changes everything: our sense of time and priorities, our experience of space, our felt relations with others, and our sense of self and of the body” (Van Manen, 1998, p. 6). Healthcare really is different than any other endeavor, especially as it relates to the customer experience. First and foremost, unlike other industries, in healthcare the consumer is actually a patient. Deloitte’s 2016 Consumer Priorities in Health Care Survey makes the following observation, “Health care consumers are unlike typical consumers. Their experiences are varied and complex as they engage with multiple parties on emotional and personal topics... The stakes are much higher in health care than in typical consumer transactions” (Read & Kaye, 2016, p. 2). A person becomes a patient typically out of necessity as opposed to choice. Press states, “All things being equal, patients never want to use your service... They are there for the serious business of diagnosis and/or cure” (Press, 2006, p. 48). In response, the aim of healthcare is to maintain and improve a patient’s overall condition with regard to illness, injury, disease, psyche, and function (Paget et al., 2011). Or to put it more succinctly, the primary purpose of health care is “to facilitate healing” (Awdish & Berry, 2019, p. 2). The implication of healing seems simple on the surface, but Awdish and Berry remind, “Each unique instance of healing represents a physical and emotional journey through difficulty” (Awdish & Berry, 2019, p. 2). Expanding from the individual to the organization or system level, Press remarks, “The keys to improving patients’ experience of care are neither obvious nor effortless. Hospitals and providers have to work at it” (Press, 2014, p. 6).

### **Understanding What Patients Want... A Miscommunication**

“Working at it” with regard to bettering the patient experience is what virtually every health care service provider has been attempting to do since the passage of the PPACA. To this

end, logic follows that understanding what the patient wants is central to any potential improvement efforts. However, the literature shows that this principle is not universally honored. A 2015 survey from HealthLeaders Media revealed that of 341 organizational respondents, only 51% ranked “delivering what the patient values” as a main concept in their patient experience program, but 93% of respondents in the same survey stated “patient satisfaction” was a top organizational priority (Bees, 2015). A 2012 paper from the Institute of Medicine reported that 80% of patients want their provider to “listen” but only 60% say that happens. Only 47% of providers reportedly ask their patients about their goals or concerns. 90% of patients said they want to see their provider teams work well together, but only 40% of patients reported observing good teamwork (Alston et al., 2012). This same study concludes, “Unfortunately... there are important differences between what providers think patients should know and what patients want to know” (Alston, et al., 2012, p. 2). One study coined the term “patient preference misdiagnosis,” referring to when a clinician makes a faulty assumption about what the patient wants. That same article points out that even though clinicians have reported that it is important to ask patients about their expectations and desired outcomes, they often fail to do so. This failure to follow through exacerbates the gap that exists between “what patients want, and what doctors think patients want” (Luxford & Sutton, 2014, p. 20).

### **From the Patient’s Perspective - Primary Drivers of Individual Patient Experience**

Research has shown that patients want their providers to “listen to me” and “communicate to me in a way I can understand” (Wolf, 2018b, p. 4). A 2018 survey from the Beryl Institute ranked the top 10 patient reported items to the patient experience. Ranked first was “listen to you” followed closely by “communicate clearly in a way you can understand”

(Wolf, 2018a, p. 10). Both of these items were ranked as very or extremely important by 95% of respondents. Number seven on that list was “provide a clear plan of care and why they are doing it” and number eight was “ask questions and try to understand your needs and preferences” rating at 93% and 92% respectively for very or extremely important to the patient experience (Wolf, 2018a, p. 10). A 2018 survey from Healthgrades found that patients place highest priority on the time spent with the doctor, particularly in answering patient questions, listening to concerns and ensuring the patient fully understands their condition and the plan of care. This same survey found that patients view healthcare as a personal interaction and not just a medically sponsored transaction. Patients reported wanting a connection with their providers (Booker, Wyatt, & Fischer-Wright, 2018). A separate 2018 report from the Beryl Institute states that their research shows the top three factors in rating the patient experience are: being listened to; being communicated to clearly in a way they can understand; and being treated with courtesy and respect (Wolf, 2018c). Deloitte reported similar results from their 2016 consumer survey. “Consumers want to be heard, understood, and given clear directions though a personalized health care experience that is not rushed” (Read & Kaye, 2016, p. 4). A different Deloitte sponsored paper showed that over 50% of respondents to a 2015 survey said they would switch hospitals due to inadequate information transparency and communication (Betts, Balan-Cohen, Shukla, & Kumar, 2016). Going back to the 2012 IOM study, the authors reported the top patient reported factor to the question “I want my provider...” was “to listen to me.” Second in that study was “to tell me the full truth about my diagnosis, even though it may be uncomfortable or unpleasant” (Alston et al., 2012, p. 3). Reinforcing the themes of “listening” and “connection,” a 2019 paper from the *Journal of Patient Experience* found that the large majority of patients want their doctors and nurses to know some personal information about them, and

that practitioners with personal knowledge about the patient could provide better care to the patient in addition to helping improve communication between the care team and the patient. However, the scope of personal information that patients felt was valuable or were comfortable sharing with the care team varied from patient to patient, serving as a reminder that the approach to care for each patient should be personalized (Zimmerman, Min, Davis-Collins, & DeBlieux, 2019).

### **Filling in the Communication Gap with Shared-Decision Making**

To overcome the gap between patient wishes and clinician assumptions, many in the literature support shifting the focus of the provider/patient interaction away from the traditional paternalistic doctor-led model to a practice style that is more equally participative. Dr. Gurpreet Dhaliwal from University of California San Francisco advocates for the adoption of a “keystone habit” that is the focus of all health care delivery - taking the “patient’s perspective” (Dhaliwal, 2016, p. 1). He exhorts health care professionals to always ask, “What do I want when I’m a patient?” (Dhaliwal, 2016, p. 2) as a means to guide decision-making and communication. Berwick provides an operational vision of Dr. Dhaliwal’s keystone habit. He declares that the ideal health delivery practice can be described as follows, “They give me exactly the help I need and want exactly when and how I need and want it” (Berwick, 2009, p. w558). Fully comprehending the implications of that one sentence and consistently delivering care services that actually meet this vision would be transformative to the care experience at the individual, system and population health levels. The beauty of this type of foundational goal is that it is focused at the individual patient level, where the care experience is born and blossoms. One method that is integral to the pursuit of Berwick’s ideal practice, and is the most direct

intervention to address the previously discussed desires of patients, is the idea of shared decision making.

Shared decision making involves the patient and the physician/provider working together in two-way communication. The physician offers treatment options and describes the risks and benefits of each potential path. The patient asks questions and communicates his/her preferences and values. Through this information exchange, a more complete understanding of all the pertinent factors in a decision is unveiled, and the decision about how to proceed is completed as a shared responsibility (Barry & Edgman-Levitan, 2012). Shared decision making is especially important when there are multiple care options that exist to address an issue, but with each option the potential costs, compliance scheme and side effects of treatment differ (Barry & Edgman-Levitan, 2012). To optimally execute shared decision making, the physician must relinquish the role as the subject matter authority and learn to value the input, and the decisions, of the patient. In other words, learning to ask “What matters to you?” and not just “What is the matter with you?” (Barry & Edgman-Levitan, 2012, p. 781). Dr. Adrienne Boissy of Cleveland Clinic calls this “relationship-centered care” where both parties must recognize that they influence each other to design a care path toward better health for the patient (Bees, 2015). Awdish and Berry refer to this concept as “mutuality.” They remark, “Mutuality requires that patients be viewed as the rightful owners of their medical records and their stories. Mutuality allows us to partner with another person, without judging or needing to be in control of his or her journey” (Awdish & Berry, 2019, p. 3). Paget and her co-authors describe shared decision making this way: “As the ultimate stakeholders, patients should expect an active role in and shared responsibility for making care decisions that are best for them. Clinicians, in turn, should



respect and support patients in this role, valuing their input and prioritizing their preferences in shaping care choices” (Paget et al., 2011, p. 1). They go on to say that this is done with the goal of “common understanding of, and agreement on, the care plan” (Paget et al., 2011, p. 3). Alston and his co-authors complement the sentiments expressed by Paget, et al. In their report, they acknowledge that the “multi-faceted decision-making process recognizes that, in most cases, there is no “right” decision” (Alston, et al., 2012, p. 3). But they go on to assert, “The answer to any given medical question is patient-specific; it depends on the medical evidence, the providers’ clinical expertise, and the unique and individual preferences of the patient” (Alston, et al., 2012, p. 3). Berwick links shared decision making to improved quality and lower costs, advocating “The more patients and families become empowered shaping their care, the better that care becomes, and the lower the costs” (Berwick, 2016, p. 1330). From a system-level perspective, Press contends the healthcare industry must progress to a “culture of patient experience” but that this can only be realized “when everyone accepts that the patient’s personal experience is as much a part of “care” as are the diagnostic procedures, surgeries, therapies and medications administered” (Press, 2014, p. 6).

### **Other Actionable Factors of Patient Experience – Care Coordination & Wait Times**

One recurrent theme in the literature that plays a role in assessment of the patient experience is care coordination. Effective coordination of care helps ensure smooth navigation of the care journey for the patient, especially as he or she crosses paths from one provider to another (primary care to specialist, for instance) or one level of care to another (outpatient to ER to ICU, etc.). Poor care coordination comes with a cost financially and clinically. Deficits in this area cost an estimated \$12 billion to \$44 billion dollars a year to the economy. In addition,

poor transitions of care often result in less than optimal health outcomes (Ryan, 2017). Plus, patients have identified in surveys that perceived good teamwork in support of their care is important to how they assess the care experience (Ryan, 2017). A 2018 study from the *Journal for Healthcare Quality* that looked at factors driving patient experience in the emergency department (ED) found “teamwork” as a significant factor in both high and low ratings for ED patient satisfaction (Aaronson, Mort, Sonis, Chang, & White, 2018). A 2018 publication on communication within VA patient centered medical home teams revealed that intrateam communication was independently positively associated with patient satisfaction rating of the PCP. The same study found that when improved intrateam communication and improved provider-patient communication were examined together, they predicted high satisfaction ratings 81% of the time (Stockdale et al., 2018). Care coordination is even more of a factor to rating patient experience for patients in poor health, as reported in a recent study published by Hays and his colleagues in *Medical Care* (Hays et al., 2018). Alston, et al., state in their 2012 paper, “People are aware that there are benefits to care coordination and believe that there care should be better coordinated. People with chronic conditions are even more aware of this need than the general population... and actively want to be involved in better-coordinated care” (Alston et al., 2012, p. 11). They go on to state that high costs for care of chronic diseases can be lessened with good care coordination and that the resulting gap is “both costly and unnecessary” (Alston et al., 2012, p. 11). However, even though clinicians are aware of the need for good intra-team communication and care coordination, the execution of the ideal remains difficult. One study conducted in the primary care setting found that information flow through an episode of care was a challenge and that misaligned goals between patients, physicians, and management are an impediment to providing or obtaining desired services (Brown et al., 2015).

Another determining factor in the rating of patient experience demonstrated consistently in the literature is wait times. The “magic number” on wait times varies in different studies, but the pattern remains the same. The longer patients wait, either in perceived wait times or actual, the less satisfied they become with their care. A report from Emory University Department of Radiology and Imaging found that patients in that practice actually perceived their waits to be about half of the actual wait times, but the pattern of lower satisfaction for longer waits was consistent. They also found that there was a precipitous drop in satisfaction scores after 35 minutes of perceived wait time (Glenn & Mahmood, 2016). A 2017 survey of 70,000 respondents who had appointments with 1,800 different PCPs across the country found that the patient’s likelihood of recommending a practice decreases with longer waits. Patients who reported waiting less than 15 minutes were likely to recommend over 70% of the time. That rating dropped to about 40% if the wait time hit 45 minutes (Gritters, 2017). An annual physician wait time survey from the Vitals Index revealed: 84% of 675 survey respondents believed wait time is important to the patient experience; 30% of patients have left appointments without being seen due to long waits; and 20% reportedly have changed doctors due to experiencing a long wait. They also found that the average wait time for 5-star rated doctors in their index was just over 13 minutes, where the one-star rated physicians averaged a wait time of 34 minutes (Larson, 2018). A 2016 study looking at data from 2011-2014 that focused on orthopedic clinic wait times and patient satisfaction found stark drops in rating of overall satisfaction in 15 minute intervals (Kreitz, T., Winters, B., & Pedowitz, D., 2016). A qualitative study that conducted patient experience focus groups in a Utah-based free clinic found that the patients reported being frustrated by long wait times, both in the clinic and when making an appointment (Kamimura et al., 2016). The previously cited study from Aaronson et al., also

found that increased wait times in the emergency department decreased patient satisfaction (Aaronson et al., 2018). A 2014 article reported that long waits not only had the expected effect of lowering patient satisfaction scores, but also found a correlation between long waits and decreased ratings of care quality and confidence in the provider (Bleustein et al., 2014). Delays in care at the time of appointment or at the time of presentation (in the case of an ED or urgent care clinic) are sometimes unavoidable. Some of the impact of long waits on patient satisfaction can be mitigated with communication and other activity. Leddy, Kaldenberg and Becker offer these thoughts on addressing the perception of a long wait, “Unoccupied wait times feel longer than occupied wait times. Uncertain waits are longer than known finite waits. Unexplained waits are longer than explained waits” (Leddy, Kaldenberg, & Becker, 2003, p. 139).

### **Financial Impact of Patient Experience**

Separating out the aspect of patient experience survey scores being part of the VBP reimbursement formula, there is a litany of other research investigating the association of patient experience and financial performance. In the case of “happy” patients and increased dollars, the large majority of studies demonstrate a positive association between increased patient satisfaction and more money into the entity. There is one notable exception. Fenton and his colleagues, using an analysis of multiyear MEPS data, found that higher patient satisfaction ratings were associated with greater inpatient admissions, higher overall prescription drug expenditures, and higher overall health care spending (Fenton, Jerant, Bertakis, & Franks, 2012). A more narrowly focused study found a link between higher facility costs and patients’ willingness to recommend the facility (Huerta, Harle, Ford, Diana, & Menachemi, 2016). All other evidence found in the literature research for this project revealed a number of positive

financial benefits to increased patient experience. A 2012 Press Ganey White Paper detailed an analysis of client satisfaction scores and hospital patient volume from 200-2004. That analysis found the hospitals in the 90<sup>th</sup> percentile on patient satisfaction saw an increase in volume of nearly one-third, serving nearly 1,400 additional patients per year. In contrast, the same study found that hospitals ranked in the bottom 10<sup>th</sup> percentile on satisfaction had an average volume decrease of 17% in the same span (Press Ganey, 2012). A 2017 Press Ganey report found that health systems with higher performance on HCAHPS “likelihood to recommend” metric have higher net margins, lower spending 30-days post hospital discharge, and receive higher reimbursements per patient episode of care than those in the bottom quartile of the HCAHPS ratings for patient experience (Ryan, 2017). A 2019 article from Buhlman and Lee report finding an association between overall hospital rating and financial performance such that for every five point increase in hospital patient experience ratings, there was a corresponding increase of 1% to net profit margin (Buhlman & Lee, 2019). Trzeciak and colleagues reported in their 2017 article that better patient experience in the hospital, based on the CMS star ratings, was associated with lower health care spending (Trzeciak et al., 2017); the opposite of Fenton’s findings from 2012. Another study reported that a positive patient experience rating was associated with profitability, while a low experience rating was even more significant in its correlation to decreased profits (Richter & Muhlestein, 2017). A study from Deloitte reported that in a 2008-2014 sample, hospitals with “excellent” HCAHPS ratings had a net margin of 4.7%, compared to average net margin of only 1.8% for hospitals with “low” HCAHPS ratings. Those differences held regardless of hospital governance or academic affiliation. They also found that hospitals with better patient ratings earn more revenue per patient day than similar hospitals with low ratings (Betts, et al., 2016). Wolf and Widmer published in their 2011 report

from the Beryl Institute that top quartile hospitals for patient satisfaction are also the most profitable, and that hospitals with bottom quartile patient satisfaction scores proved to be the least profitable (Wolf and Widmer, 2011).

### **Other Benefits to Better Patient Experience**

In addition to better revenues and profit margins, the patient experience literature also shows a strong association between higher patient experience ratings and decreased malpractice rates and fewer malpractice claims (Betts et al., 2016; Browne, et al., 2010; Mayer & Cates, 2014; Press, 2006). Stelfox and colleagues found that for every one point decrease in patient satisfaction there was a five percent increase in risk management episodes for the organization (Stelfox, Gandhi, Orav, & Gustafson, 2005). The literature also demonstrates a relationship between increased employee satisfaction, lower turnover rates, and higher patient satisfaction scores (Baird, 2011; Betts, et al., 2016; Browne, et al., 2010; Mayer & Cates, 2014; Press, 2006).

Ultimately, the literature shows that raising health care experience ratings positively impacts patient loyalty, including word-of-mouth commentary. Fred Lee expounds on the importance of loyalty in his 2004 book, “If the only real source of loyalty is patient experience, and the only test of experience is what the patient says about it, learning what creates the best experience should be (leadership’s) primary goal” (Lee, 2004, ch. 3, loc. 968, Kindle). Earning loyalty from a patient is not easy and cannot be accomplished simply by meeting clinical expectations. Clinical competence is expected. Loyalty is only earned through exceeding the patients’ experience expectations (Baird, 2011; Lee, 2004; Mayer & Cates, 2014). Mayer and Cates point out that loyal patients trump unhappy patients. They report that loyal patients will tell 40-50 people about their experience, while unsatisfied patients will tell about 20 (Mayer &

Cates, 2014). Wolf and Widmer found that patients who had a bad experience would tell about 25 other people, while merely “satisfied” patients would tell on average 3 other people (Wolf & Widmer, 2011). Multiple recent publications show a decisive link between the patient experience and loyalty. A 2018 Press Ganey white paper found that patient experience is five times more likely to influence brand loyalty than any other marketing or advertising effort. That same survey found the top two drivers of patient loyalty, defined by choice to give repeat business, to be the patient’s most recent health care experience (74%) and the second highest determinant was the experience of family and friends (55%) (Press Ganey, 2018). One recent Beryl Institute report showed that 76% of patients with a “bad” care experience would tell other people. The same report revealed that 43% of patients with a “bad” experience would not return to the same provider or practice; and 37% of those with a “bad” experience would find another healthcare organization altogether if possible (Wolf, 2018c). A separate report from the Beryl Institute shows that 91% of respondents rated the patient experience as “significant” to making healthcare choices. That report also exhibited that 73% of respondents who had a “good” patient experience would continue to use the same doctor or hospital (Wolf, 2018a). 95% of respondents to a 2015 survey showed that experience was significant in making healthcare utilization decisions not just in the moment, but for future health care needs as well (Wolf, 2015). The bottom line is that patient experience, either good or bad, has a tangible impact on financial outcomes, repeat business, and brand loyalty.

### **Patient Experience and Quality of Care**

The literature produces mixed conclusions regarding the assertion that patient experience is integral to, a component of, or an appropriate proxy for healthcare quality. Some argue that

regardless of the true technical outcome related to care rendered, the patient perception is the trump card when assessing the quality of that care. Berwick states simply, “Patients’ experiences should be the fundamental source of the definition of quality” (Berwick, 2002, p. 80). A 2017 report from Press Ganey explains, “Patients’ perceptions of their care can be considered a surrogate for the degree to which an organization delivers on its promise to provide safe, quality, patient-centered care... patients know safe, quality care when they see it” (Ryan, 2017, p. 7). Press is more direct, emphasizing, “If a hospital’s patients are dissatisfied with care, then that care is of lower quality, regardless of the subsequent technical outcome” (Press, 2006, p. 6).

Manary and his co-authors make a different, but logical, argument for improving the patient experience. They contend that “debate should center not on whether patients can provide meaningful quality measures, but on how to improve patient experiences by focusing on activities (such as care coordination) found to be associated with both satisfaction and outcomes” (Manary, Boulding, Staelin, & Glickman, 2013, p. 203). Farley, et al., agree with the use of patient experience as a measure of patient-centered care and with its inclusion in payment programs, but feel that it should be a distinct outcome measure representing it as a valuable goal in and of itself. However, they concluded that “patient satisfaction is not a validated proxy for quality” (Farley et al., 2014, p. 354). Price et al., draw a similar conclusion, stating that, “Patient experience measures *complement* measures of technical care quality by generating information about aspects of care for which patients are the best or only source, such as the degree to which care is respectful and responsive to their needs” (Price et al., 2014, p. 534). The same argument has been supported by Kennedy and his colleagues regarding patient satisfaction and patient safety. They state that patient satisfaction is “clearly a separate quality measure but is not a



surrogate for patient safety and effectiveness (as applied to favorable surgical outcomes)” (Kennedy, Tevis, & Kent, 2014, p. 597). A 2013 article from Lyu and her colleagues shows the same findings as Kennedy’s group. In their study, patient satisfaction was found to be independent of compliance with surgical quality of care processes and overall employee safety culture (Lyu, Wick, Housman, Freischlag, & Makary, 2013).

While the literature is not conclusive with regard to whether patient experience should be used as a proxy for healthcare quality, or even used to define quality of care; it does demonstrate that there has been a multitude of evidence that higher patient experience scores are strongly associated with healthcare quality and patient safety. In their review and subsequent report, which analyzed the findings of 33 published works, Price et al., concluded that the research indicates patient care experiences “are associated with higher levels of adherence to recommended prevention and treatment processes, better clinical outcomes, better safety in hospitals, and less health care utilization” (Price et al., 2014, p. 535). In the systematic review that included 55 articles accomplished by Doyle, Lennox and Bell, they found the same positive associations for patient safety, patient outcomes, and adherence to medication and treatment plans. They also reported evidence in the literature to support positive associations between patient experience ratings and preventive care screenings and immunizations (Doyle, Lennox, & Bell, 2013). On screening services, they detail that the associations extend to screening tests for breast and cervical cancer, colorectal cancer, diabetes, and high cholesterol. They clearly point out that associations are not causality. Nevertheless, they conclude that the research supports the conclusion that patient experience, patient safety, and clinical effectiveness are linked (Doyle et al., 2013). Price’s group details that the research demonstrates the highest performing

organizations on HCAHPS also perform significantly better in process measures related to AMI (heart attack), congestive heart failure, pneumonia, and surgery. Conversely, the literature shows that the lowest ratings on willingness to recommend were linked to poor performers on cardiac process measures (Price et al., 2014). Price et al., make a point to note that the studies included in their review also demonstrate that there is no trade-off between a highly rated patient experience and strong performance on clinical quality outcome measures or process compliance measures. Their review supports that best practices for experience, processes, and outcomes are associated across organizations (Price et al., 2014). Johnston and her colleagues performed a similar meta-analysis published in 2016. They found, like their predecessors, that hospitals with lower AMI, heart failure, and pneumonia readmission rates and mortality rates scored higher across HCAHPS measures. Johnston's team concluded that the "consistent confirmation of the relationship between clinical quality and patient satisfaction provides support for inclusion of HCAHPS in the VBP formula" (Johnston, Johnston, Bae, Hockenberry, & Milstein, 2016, p. 86).

The evidence collected and collated by those earlier systematic reviews have been upheld by later works. Trzeciak and colleagues found a significant association between higher CMS Hospital Star Ratings and multiple clinical outcomes. These include lower rates of readmission for: AMI, CHF, pneumonia, stroke and COPD. They also found lower rates of hospital complications for: central-line acquired bloodstream infection, postsurgical deep vein thrombosis, joint replacement complications, accidental puncture or laceration, and iatrogenic pneumothorax (Trzeciak, Gaughan, Bosire, & Mazzairelli, 2016). A 2015 study from Tsai, Orav and Jha confirmed that surgical quality and better patient experience ratings are not exclusive. They showed that hospitals with highest patient satisfaction had lower 30-day readmission rates,

shorter hospital length of stay, and lower mortality rates for surgical patients. They found that the hospitals with the highest patient satisfaction scores also had the highest composite surgical quality. However, like earlier studies, they explicitly state that these findings do not prove causality (Tsai, Orav, Jha, 2015). Dr. Thomas Lee recently reported findings that top quartile organizations for patient experience also have significantly better clinical quality metrics (lower length of stay, lower 30-day readmission rates, lower rates of hospital acquired conditions), better safety records and report better financial margins than bottom quartile patient experience performers (Lee, 2019). This chorus of studies, that echo the same, or very similar, associations between patient experience and various aspects of technical clinical quality, does not establish causality. However, maybe the explanation is just as simple as “doing the right thing” (operationally defined as providing necessary and appropriate treatment) consistently results in improved patient experience (Tajeu, Kazley, & Menachemi, 2015).

### **Demographic Characteristics Related to Patient Experience**

The literature has broken down the various demographic factors that relate to patient experience ratings into three main categories: the patient level, hospital/organization level, and market level. At the patient level there is not complete consistency on the role different personal characteristics play. A 2017 systematic review of the literature found that minority racial and ethnic groups generally had less positive hospital experiences. They also reported that older patients and women reported lower satisfaction (Mazurenko, Collum, Ferdinand, & Menachemi, 2017). However, a different systematic study found that hospitals with more older and female patients reported consistently higher patient satisfaction scores in their analysis (Johnston, Johnston, Bae, Hockenberry, & Avgar, 2015). Johnston and her colleagues found the same

results as Mazurenko et al., regarding ethnic minorities consistently reporting lower satisfaction than whites. Both Johnston's team and Mazurenko's review found that patients with poor-health status reported consistently lower patient experience scores (Johnston et al., 2015; Mazurenko et al., 2017). The same goes for insurance status, where both found that more Medicaid patients meant lower satisfaction scores (Johnston et al., 2015; Mazurenko et al., 2017). A 2018 study found that patients who were younger, male, African American, with Medicaid and lower socioeconomic status were more likely to report poor satisfaction. They also found those with poor mental health and more than two ED visits were more likely to report low satisfaction (Chen et al., 2018). However, there are some studies that refute the associations related to race. A 2014 study looking at VA patients found that men were more satisfied than women in the same hospitals. In addition, it found that black and Hispanic patients both reported more positive experiences in the same hospitals versus white patients (Hausmann, Gao, Mor, Schaefer, & Fine, 2014). A 2016 report published in *Health Affairs* found that there was no comparable difference on patient experience ratings between black and white patients in the same hospitals. This same group also found that higher level of education and self-reported poor health status were associated with lower patient satisfaction scores for both whites and blacks (Figuroa, Zheng, Orav, & Jha, 2016). A 2018 article in *Journal for Healthcare Quality* reported that Hispanics were more likely than whites in the same hospital to recommend their hospital as 9 or 10 on HCAHPS for overall experience of care (Figuroa, Reimold, Zheng, & Orav, 2018). A 2005 report from the Commonwealth Fund found that patients who were uninsured and low-income were six times more likely to report dissatisfaction with their care. They also found the same inverse correlation as other studies mentioned regarding poor health status and satisfaction. This report framed these issues around patient "choice," with patients equating no insurance, poor

health, and low income to greatly limiting, or completely limiting, their healthcare related choices. This same study found patients reported general satisfaction with employer-based insurance (Lambrew, 2005). In summation, poorer health status, uninsured or Medicaid, and higher-level education all seem to consistently lead to lower patient satisfaction scores at the individual level. The findings on differences in race and sex were mixed. Most studies found that older patients also give higher ratings of satisfaction.

At the hospital level: safety net hospitals, those with higher levels of Medicaid and uninsured, higher patient severity (poorer health status), and high minority populations were all associated with lower patient experience scores (Chatterjee, Joynt, Orav, & Jha, 2012; Elliott et al., 2010; Elliott et al., 2016; Johnston et al., 2015; Mazurenko et al., 2017; Merlino et al., 2014; Neuhausen & Katz, 2012). Hospitals with higher populations of non-English as preferred language were also found to have lower scores (McFarland, Ornstein, & Holcombe, 2015). Conversely, hospitals found to have higher patient experience scores are small (100 beds or less), have higher percentage of Medicare or privately insured patients, have more white patients, and less medically complicated patients. They also showed to have higher nurse to patient ratios (Johnston, et al., 2015; Lehrman et al., 2010; McFarland, Ornstein, & Holcombe, 2015). Non-teaching hospitals reported significantly higher scores than teaching facilities (Johnston et al., 2015).

At the market level, Kazley and her colleagues found the availability of specialty practitioners (access to care) to be the most consistent factor for better patient experience ratings. Availability of general practitioners and increased per capita income were the most consistent factors corresponding to lower satisfaction ratings. Metropolitan status was negatively

associated as well, but higher competition in the market (more provider choice) was associated with higher satisfaction scores (Kazley, Ford, Diana, & Menachemi, 2015).

It should be noted at this point that there are legitimate reasons for hospitals to worry about the composition of the VBP formula, especially with regard to the portion of it that pertains to HCAHPS scoring. The information from the literature clearly demonstrates that the institutions depended upon the most to serve the uninsured, low-income, most medically complex, and most vulnerable patients in society are also at greatest risk for being penalized in the current VBP formula. There is nothing that can be done about the composition of the patient population our teaching/academic and safety net hospitals serve. Indeed, those same institutions play a crucial role in overall community health. But many of these same hospitals also run with deficits or very small operating margins because of the payer mix challenges inherent with serving those dependent upon public health services. Policy makers should absolutely revisit the formula for VBP as it relates to these critical institutions around the country. One of the goals of public health policy is to close the gaps in health disparities. An unintended consequence of the current VBP model could be to exacerbate those gaps by undercutting the organizations that serve the public good.

### **Impact of Surveys and the Value-Based Purchasing Program**

At this juncture, the application of the VBP program is in full swing and hospital organizations all across the country are making their respective best efforts to meet or even exceed the standards of pay for performance. However, has the VBP program actually pushed improvement in patient experience ratings? That answer appears to be no, for the moment. One study from *New England Journal of Medicine* published in 2017 found that there was no

difference in patient experience measures in VBP program hospitals versus critical access hospitals (which are not subject to VBP) for the first four years of the VBP program (Ryan, Krinsky, Maurer, & Dimick, 2017). Another 2017 study looking at data from 2008-2014 found that patient experience measures had improved modestly across the U.S., but that there was no difference in VBP and non-VBP hospitals. In addition, they found that the majority of the improvement in scores occurred before the implementation of VBP (Papanicolas, Figueroa, Orav, & Jha, 2017). In contrast, a 2010 study in *Health Affairs* found that “public reporting” of patient experience scores from HCAHPS had helped to drive “modest but meaningful” improvement across all experience measures, except doctors’ communication, and that these findings held across all hospitals (Elliott et al., 2010). These studies do not mean that the desired impact of VBP for patient experience is completely missing. It could just mean that the real catalyst for change at the hospital and system level was transparency of the scores, not the threat of financial penalty. Or, it could simply mean that more research needs to be done with regard to the impact of VBP as it matures. At this point, further study is warranted.

With regard to HCAHPS itself, there are issues that have been illustrated in the literature that are worth noting, both with the mechanics and the application of survey results. One issue regarding the mechanics of the survey has to do with response rate. Earlier works argue that non-response bias is not an issue, and that the process of HCAHPS survey collection holds to the highest standards for survey implementation. One early study contends that “there is no scientifically proven minimally acceptable response rate” (Tefera, Lehrman, & Conway, 2016). However, a study just published in 2019 refutes these assertions. Godden and her colleagues, looking at a national sample of HCAHPS scores, found that a higher response rate was positively

correlated with increased experience scores. They concluded that these findings could mean that the low response rates for HCAHPS (nationally around 30%) are masking individual hospital performance and that improvements to patient experience might actually be more widespread than what is currently reported (Godden, Paseka, Gnida, & Inguanzo, 2019).

Conflicting messages like the literature has shown on the mechanics of official patient experience surveys and the mixed conclusions that researchers have reached regarding using patient satisfaction scores as a proxy for judging quality have been a bone of contention for those in clinical care, especially physicians. A 2019 survey of physicians found that 59% of 544 respondents felt that available survey instruments are “not effective” in measuring patient experience (Ransco, 2019). A 2015 study of 143 healthcare organizations reported that while Boards and CEOs consistently viewed the patient experience as “extremely important,” only 15% of respondents reported physicians were supportive of efforts to measure and improve the patient experience. Only 34% of respondents reported nurses being supportive and committed to patient experience reporting and improvement (Manary, Staelin, Kosel, Schulman, & Glickman, 2015). Zgierska and his colleagues reported on a limited sample survey (only 155 physicians responded of a possible 4,000) finding that use of survey data was a dissatisfier for physicians and nearly half of the respondents believed the pressure to obtain better “patient satisfaction” scores promoted inappropriate care, including unnecessary prescriptions for antibiotics and opioids, and unneeded testing and procedures (Zgierska, Rabago, and Miller, 2014). 59% of the 155 survey respondents reported having pay incentives of some kind tied to patient satisfaction ratings. The authors concluded that financial incentives for physicians tied to giving or telling



the patients “what they want” to keep satisfaction ratings high could have the unintended consequences of compromised or inappropriate care (Zgierska, Rabago, and Miller, 2014).

### **Actionable Factors Impacting Patient Experience**

In examining the literature regarding the items on patient experience surveys that are the biggest drivers of overall experience ratings, there is a clear theme. Communication is king. Multiple studies confirm that MD communication is vitally important in this regard (Kahn, Iannuzzi, Stassen, Bankey, & Gestring, 2015; Mills et al., 2015; Shirley & Sanders, 2013). Nurse communication is equally as important, based on the literature (Kutney-Lee et al., 2009; Press Ganey, 2013; Yavas et al., 2016). Timeliness of care and pain management were also shown to impact overall rating of care (Welch, 2010). Staff courtesy ranked second in one study that was done (Van de Ven, 2014). Cleanliness was a major factor in one study as well (Yavas et al., 2016). Kahn et al., found that inside the communication categories, doctors’ listening, nurses’ listening, and doctors’ explanations were the most significant (Kahn et al., 2015). Iannuzzi and his colleagues found that pain management was an important driver of satisfaction. They also found that good patient-centered communication can mitigate an unexpected or suboptimal clinical outcome (Iannuzzi et al., 2015). Torpie summarizes the influencers with this statement, “They (patients) want safe, effective, timely care from skilled clinicians who are able to make them personally cared for, included in decision-making, and comfortable. Every patient wants to be personally cared for as an individual” (Torpie, 2014, p. 7).

### **Strategies for Improvement of Patient Experience**

1. Start with articulating a clear, shared purpose and vision incorporating patient experience at the heart of the message. The purpose needs to include corresponding expectations and

assignments for leadership and staff members to ensure accountability. Know what goals you are trying to achieve and what success looks like. Leadership sets the tone (Merlino & Raman, 2013; Snyder, 2017).

2. From the purpose and vision, a cultural commitment must follow. This includes consistent and persistent messaging about the importance of the patient experience, commitment to training for staff at all levels, on an ongoing basis, and transparency to your stakeholders, both patients/families and employees (Birklien, 2017; Guler, 2017; Snyder, 2017; Wolf, 2017a).
3. The efforts made for patient experience should be tied to quality and safety. All elements impact the patient experience. Recognize and embrace the interconnected nature of these concepts as your foundation and frame improvement efforts with all aspects in mind. No more silos (Ryan, 2016; Sanchez & Hermis, 2019; Wolf 2017b)!
4. Engage the clinical staff and clinical leadership. Nothing will work without their full participation. After all, they are actually delivering the patient care (Guler, 2017).
5. Use data to the fullest extent possible. Gather, analyze, disseminate and learn some more. The cycle of continuous learning and improvement continues with consistent use of the data (Guler, 2017; Merlino & Raman, 2013; Snyder, 2017).
6. Engage the patients/families. Solicit their feedback actively and make it as easy as possible for them to access their care team members and administrative leadership (Birklien, 2017; Wolf, 2017a).
7. Institute hourly clinical rounding and daily administrator/leadership rounding. It's the one "tactic" from the literature that proves to be a maintainable activity with real payoff (Guler, 2017).
8. Commit to employee engagement. Engaged staff deliver better service on a more consistent basis (Wolf, 2017a).

## **CHAPTER III METHODOLOGY**

### **Research Question and Hypotheses**

This project proposed to answer the question, "*Is there a significant predictive relationship between health literacy and overall rating of patient experience?*" The hypothesis

of this study is that higher ratings of overall patient experience are associated with higher levels of reported understanding for both explanations and instructions. The null hypothesis is that no association (positive or negative) between ratings of healthcare experience and reported understanding of explanations or instructions exists within this dataset. The rationale behind the hypothesis is that if a patient understands his/her health better via clear instructions and better explanations, then that elevated health literacy for the patient should lead to a higher rating of the overall care experience.

### **Data Source and Sample Size**

The MEPS was chosen as the data source for this exploration for a number of reasons. First, the MEPS is an annual national survey conducted by AHRQ. As such it is a proven and verified survey instrument that is meant for data collection on a large scale, with the intent that the data will be utilized in support of research initiatives and informing health policy and operational decision making. Second, the datasets for the MEPS are free of charge and publicly available for download and use. In addition, the questions used on the 2012 MEPS are replicated on other versions of the MEPS in other survey years. This means that the data used for this project are freely and easily available to other parties who might want to replicate this study, or conduct a similar analysis with data from other years or other forms of the survey. Third, the questions selected from the MEPS for this project mimic those found within the CAHPS family of surveys used for the Value Based Purchasing program nationwide. Finally, the MEPS has a substantial “n” size, which should increase the statistical power of the subsequent analysis and the confidence in any statistical relationships that are found. The original “n” size for the 2012 survey was 11,686 respondents and this exploration uses a final “n” of 9,306, after controlling

for all the variables in the data analysis. The records expunged from the dataset were for respondents who had not indicated any healthcare visits in the last 12 months.

### **Data Analysis Methodology and Process**

Using the publicly available dataset from the Medical Expenditure Panel Survey (MEPS) for 2012 (published by AHRQ at <https://meps.ahrq.gov/mepsweb>), this project looked for a statistically significant relationship between two measures of health literacy from the viewpoint of respondent self-reported understanding and the overall rating of healthcare experience. The Medical Expenditure Panel Survey (MEPS) 2012 Adult Self-Administered Questionnaire survey tool is the source of the data analyzed for this project (retrieved from:

[https://meps.ahrq.gov/survey\\_comp/hc\\_survey/paper\\_quest/2012/2012\\_SAQ\\_ENG.pdf](https://meps.ahrq.gov/survey_comp/hc_survey/paper_quest/2012/2012_SAQ_ENG.pdf)).

Specifically, a comparison was made between health literacy as represented by two questions which serve as the independent variables for the study: “In the last 12 months, how often did doctors or other health providers explain things in a way that was easy to understand (question 9 of 46 on the survey) ?,” and “In the last 12 months, how often were these instructions easy to understand (question 13 of 46 on the survey) ?,” and the overall rating of patient healthcare experience, which serves as the dependent variable for the study, as recorded through responses to question 17 on the survey, “Using any number from 0 to 10, where 0 is the worst health care possible and 10 is the best health care possible, what number would you use to rate all your health care in the last 12 months (Agency for Healthcare Research and Quality, 2012b)?” This comparison was performed statistically utilizing binary logistic regression analysis. For the purposes of the analysis, the independent variable “Health Literacy” was made into one variable with an additive score of 8, categorized as: 2-4 = Low Health Literacy; 5-7 = Moderate Health

Literacy and 8 = High Health Literacy. For the dependent variable, Patient Healthcare Experience Score, 9-10 = Pass and <9 (8 or below) = Fail.

Binary logistic regression was used in this study so as to mirror the “pass or fail” model of analysis for current patient experience surveys where only the rating of 9 or 10 equals a passing score and all scores 8 or below are considered a failing result. The reason for this approach is to approximate the way overall rating of experience is gauged on the CAHPS and HCAHPS surveys that most healthcare entities utilize as part of the CMS Value Based Purchasing program. CAHPS for outpatient and HCAHPS for inpatient services use a “top-box” method for overall rating of experience, where only a score of 9 or 10 is considered to be passing on a 0-10 scale.

The analysis accounted for other factors shown in the literature to influence patient experience ratings. The factors included in the model are: age, sex, family income, education level, health status, type of insurance, and access to care (getting an appointment when wanted and ease of getting needed care). This analysis was conducted in three-stages. Model one was to establish the baseline association of health literacy and patient experience scores. Model two added in the demographic factors of age, gender, education, race, and health status (good health), and a check of the health literacy to patient experience score relationship was conducted. Model three completed the analysis with all potential associated variables included in the model, adding in access to healthcare, insurance status, and socioeconomic status. The aim of the project was to determine the predictive value, if any, of health literacy on overall rating patient experience. Other significant correlations determined from the analysis are included in the results and discussion.

## CHAPTER IV RESULTS

**Table 1: Demographics and Clinical Characteristics**

	Overall (n = 9,306)	“Fail” Patient Experience Score (n = 4,533)	“Pass” Patient Experience Score (n = 4,733)	p value
Literacy				
<i>Low Literacy % (n)</i>	2.7 (250)	4.9 (226)	0.1 (24)	
<i>Moderate Literacy</i>	45.3 (4,217)	62.4 (2,855)	28.8 (1,362)	
<i>High Literacy</i>	52.0 (4,839)	32.6 (1,492)	70.7 (4,347)	< 0.001
Education				
<i>High School</i>	70.6 (6,572)	70.3 (3,216)	70.9 (3,356)	
<i>Graduate School</i>	5.5 (514)	5.3 (241)	5.8 (273)	
<i>College</i>	23.9(2,220)	24.4 (1,116)	23.3 (1,104)	0.318
Race				
<i>White</i>	53.9 (5,017)	51.9 (2,373)	55.9 (2,644)	
<i>Black</i>	18.9 (1,755)	20.1 (917)	17.7 (838)	
<i>Hispanic</i>	19.1 (1,779)	19.0 (867)	19.3 (912)	
<i>Other</i>	8.1 (755)	9.1 (416)	7.2 (339)	< 0.001
Female Gender	61.2 (5,696)	60.1 (2,745)	62.3 (2,951)	0.022
Good Access to Healthcare	89.9 (8,370)	84.8 (3,878)	94.9 (4,492)	< 0.001
Insurance Status				
<i>Uninsured</i>	9.9 (917)	12.3 (564)	7.5 (353)	
<i>Public Insurance</i>	25.7 (2,389)	25.8 (1,178)	25.6 (1,211)	
<i>Private Insurance</i>	64.5 (6,000)	61.9 (2,831)	67.0 (3,169)	< 0.001
Low Socioeconomic Status	21.6 (2,011)	23.6 (1,077)	19.7 (934)	< 0.001
Age [mean (SD)]	51.2 (17)	48.8 (17)	53.6 (17)	< 0.001

\*All values are reported in %(n) unless otherwise specified

Table 1 presents the results of the univariate comparison, with overall percentage and “n” for each variable presented in the model, displayed by overall, failing patient experience score and passing patient experience score. Several of the items prove to be statistically significant based on the p value. The items of statistical significance primarily follow-suit with evidence from previous literature for associations with patient experience ratings.

**Table 2: Predicting a Passing Score on Patient Experience**

**Table 2: Multivariate Analyses**

Variables	Model 1		Model 2		Model 3	
	AOR (95% CI)	adjusted p	AOR (95% CI)	adjusted p	AOR (95% CI)	adjusted p
Literacy						
<i>High Literacy (reference)</i>	Reference	NA	Reference	NA	Reference	NA
<i>Moderate Literacy</i>	0.21 (0.20, 0.23)	0.04	0.21 (0.19, 0.23)	<0.001	0.21 (0.20, 0.23)	<0.001
<i>Low Literacy</i>	0.05 (0.03, 0.07)	<0.001	0.05 (0.03, 0.08)	<0.001	0.06 (0.04, 0.09)	<0.001
Age (each year)	<i>Not included</i>		1.02 (1.01, 1.03)	<0.001	1.02 (1.01, 1.03)	<0.001
Female Gender	"		1.17 (1.07, 1.28)	<0.001	1.17 (1.07, 1.29)	<0.001
Education	"					
<i>High School (reference)</i>	"		Reference	NA	Reference	NA
<i>Grad School</i>	"		0.89 (0.73, 1.08)	0.379	0.86 (0.70, 1.05)	0.25
<i>College</i>	"		0.94 (0.84, 1.04)	0.929	0.93 (0.83, 1.04)	0.962
Race	"					
<i>White (reference)</i>	"		Reference	NA	Reference	NA
<i>Black</i>	"		0.83 (0.74, 0.94)	<0.001	0.86 (0.76, 0.98)	0.012
<i>Hispanic</i>	"		1.23 (1.09, 1.39)	<0.001	1.31 (1.15, 1.49)	<0.001
<i>Other</i>	"		0.77 (0.65, 0.92)	0.002	0.79 (0.67, 0.93)	0.001
Good Health	"		1.44 (1.29, 1.60)	<0.001	1.37 (1.22, 1.53)	<0.001
Good Access to Healthcare	"		Not Included		2.01 (1.70, 2.38)	<0.001
Insurance Status	"		"			
<i>Private Insurance (reference)</i>	"		"		Reference	NA
<i>Public Insurance</i>	"		"		0.98 (0.87, 1.11)	0.069
<i>No Insurance</i>	"		"		0.76 (0.64, 0.89)	0.001
Low Socioeconomic Status	"		"		1.02 (0.90, 1.16)	0.731

**Table 2** shows the results of the multi-stage logistic regression analysis. Of note, there is clearly a positive predictive association between health literacy and a passing score for patient experience. This correlation holds up through the entire three-stage analysis.

The initial model shows low literacy patients to be 95% less likely than high literacy patients to give a passing patient experience score. It shows moderate literacy patients to be 19%

less likely to give a passing score than high literacy patients. Model two adds in the demographic variables that have been shown from the literature to hold associations with patient experience ratings. These include age, gender, education level, race and self-reported health status. As can be seen in the table, the associations for health literacy and patient experience scores revealed in model one's results hold steady for model two. The inclusion of the demographic data does not infringe on the positive association between health literacy and the probability of giving a passing patient experience score. Model two also shows statistically significant associations for gender, age, race and health status. These associations are expected and fall in line with past patient experience literature. The final stage of the analysis, model three, adds in variables for access to care, insurance status and income status.

The health literacy association remains intact through the whole regression model after controlling for all other variables. The final model shows that *those with low health literacy are 94% less likely to give a passing score for patient experience* than patients with high health literacy. It also shows that moderate literacy holds at being 19% less likely than high health literacy patients to give a passing score. The effect of low health literacy on the likelihood of giving a passing patient experience score is both statistically and operationally significant. These results show the strength of this association is meaningful enough that improvement activities in the realm of health literacy are worth the time and resources needed to make positive changes with regard to patient experience.

There are other associations revealed in this model which merit mention. Good access is significantly correlated with giving a passing patient experience score. In fact, those who reported having good access to care were two times as likely to give a passing score than those



without good healthcare access. This is the second most impactful variable for the likelihood of giving a passing patient experience rating in this model. Although the effect is not as strong as low health literacy, the results on access to care bear attention from an operational perspective, and are worthy of energy and resources in order to problem-solve the issues of access to care. Better access is highly likely to positively impact patient experience scores. Health status is the third most impactful variable in the model. Being in self-reported good health means one is 37% more likely to give a passing patient experience score than a patient with self-reported poor health. Age is positively associated with giving a passing patient experience score such that the likelihood of a passing score increases 2% with every 1 year of age. This is not that big a deal for an age difference of a few years, but if you model an age difference of 20 or 30 years, then the positive association of age to better patient experience scores becomes very significant. For gender, women are 17% more likely than men to give a passing score, based on these results. For Race, blacks were 14% less likely than whites to give a passing score, while Hispanics were 31% more likely than whites to give a passing patient experience score. The resulting association for no insurance also follows with the literature. Uninsured patients in this analysis are 24% less likely to give a passing patient experience rating when compared to those with private insurance. There was no statistical significance found for socioeconomic status or for education level. This was a bit of a surprise. Lower income has been found in some studies to have a negative correlation with patient satisfaction scores. That result did not appear in this model. In the literature, some studies had found higher educational attainment to be correlated with lower patient satisfaction scores. However, this analysis found no statistically significant relationship.

## **CHAPTER V CONCLUSION**

### **Discussion of Results:**

The results of the analysis showed a statistically significant correlation between patient reported understanding (our measure for Health Literacy) and overall rating of patient experience. These results support the working hypothesis of the project, that health literacy and patient experience rating would be positively correlated. Additionally, the analysis revealed that access to care was a significant contributor to the reported patient experience. The link between access and patient experience ratings would be of benefit for future study as well. The most important message of these results to the field is that industry leaders (administrators and clinicians alike) can actually do something about improvement of both health literacy and access to care. These findings represent “actionable” intelligence for improving the overall patient experience.

### **Limitations:**

This is a retrospective study of a large dataset from one year’s worth of results from the MEPS annual survey. While the MEPS is a proven, robust annual exercise conducted by AHRQ; it is not meant to look specifically at either patient experience ratings or health literacy issues. Additionally, a one year sample limits generalizability of the results.

### **Future Research:**

The issue of a narrow chronological sample can be easily remedied. Future studies can replicate the analysis methods used in this paper for other years of the MEPS data. The questions utilized in the analysis are used across several iterations of the MEPS. Replicating the methods of this project with other years could add weight to the correlation found in this analysis, should the

same positive predictive relationship continue to occur. In addition, there are other time-tested and proven national surveys conducted by AHRQ and other agencies that use the same or very similar questions. The analytical methods of this study could be applied to other large datasets to explore the presence of the health literacy/patient experience relationship in other survey samples.

Broadening the data pool from other surveys and the years examined can help lend weight to the presence of the health literacy/patient experience relationship found in this exploration. Further explorations of this kind are recommended to solidify the findings of this study.

More powerful research to further detail the relationship between health literacy and patient experience ratings would be to look at an actual practice or group of practices where patients are screened specifically for health literacy ability using one of the researched and accepted health literacy screening tools and then those same patients are surveyed for their impressions on patient experience. This could be done for both inpatients and outpatients, in primary, specialty and ancillary care settings. Such systematic exploration of the topic should help illuminate how important the health literacy/patient experience relationship really is to practice success for community reputation and Value Based Purchasing program success. Other known patient experience correlates, like access, wait times, and environment of care could be included in these studies. The results of studies like these can help to inform health care leaders on the best uses of system resources, time, and manpower to improve the patient experience.

### **Conclusions/Implications**

This analysis clearly shows that health literacy and overall patient experience are related and positively correlated. Based on the findings in this study, by focusing on improvement of health literacy, a corresponding improvement in patient experience ratings should follow.

The correlation found between access and patient experience is also noteworthy for practice improvement reasons. In other words, if the patient cannot get services timely, then patient experience will suffer regardless of the quality of service once it is rendered. Focusing on bottlenecks to access represent a real opportunity for improving patient experience ratings overall.

The literature in both patient experience and health literacy shows tremendous cross-over, especially in revealing tactics and strategies for improvement in these arenas. The standout takeaways are:

1. Improvement in these areas can only be maintained as a core component of organizational culture. If not fully ingrained in the culture, process improvement/quality improvement efforts may show temporary results, but not long-term sustainability.
2. Cultural commitment to these areas must be modeled and espoused consistently from the top levels of the organization.
3. Strategic goals for the organization at all levels need to include specific attention to both health literacy and patient experience.
4. C-suite level or other defined organizational roles should be designated for both health literacy and patient experience. I would recommend that these fall under the same office and are closely aligned and affiliated with the organizational efforts at patient safety, patient education, quality management and any other “survey” or “accreditation” related areas.
5. Data is incredibly important to improvement and maintained success in these areas. Health literacy and patient experience can only be targeted if they are measured, analyzed, and then the results are communicated widely and integrated strategically into tactics and metrics for improvement.
6. Internal organizational assessments for both health literacy and patient experience should become a regular business practice.

7. Organizations should commit to the use of the HL-CAHPS. It is not mandated at this time by CMS but would be a great tool for linking both concepts through a formally tested and government approved survey tool.
8. Education on these topics at all levels has to be a component of organizational practice. Health literacy and patient experience related concepts must be injected into New Employee Orientation and then reinforced through mandatory annual training and annual competency reviews.
9. Health literacy assessment tools should become a part of patient screening for both inpatients and outpatients, just like pain assessment, chief complaint, and medication review. Likewise, patient experience surveys, or at least key components of them, need to be part of patient exiting for inpatient discharge and outpatient clinics alike.
10. In order for any strategy or initiative to work, Physician and other Clinician Champions have to help lead the effort. A mandate alone that comes from the “suits” or even the Board of an organization will not accomplish the desired results long-term. Implementation cannot happen without buy-in from the clinical staff and clinical leadership.

From a policy perspective, integrating patient experience into the Value Based Purchasing program for CMS was a game changer. To elevate health literacy similarly, performance measures integrated with HEDIS or CMS reporting would likely be needed and accreditation efforts like Joint Commission, Magnet status, and PCMH certification would need to make health literacy a point of emphasis for survey success. With so many competing regulatory and business demands in the healthcare field today, inclusion of health literacy into the payment and/or accreditation structure would be necessary to get most organizations to pay the topic much attention. This is evidenced by the fact that Health Literacy has been a stated national policy goal since its inclusion on the *Healthy People 2010* plan, but while the topic has maintained a presence in national health policy, it lacks financial emphasis and is therefore largely overlooked. To be blunt, most health care leaders prioritize time to the issues that impact the bottom line directly, not tangentially.

While there is consensus regarding the viewpoint that health literacy is an integral component of health related communication, the concept itself must be thought of as “dynamic,” viewed through “a variety of lenses, depending on one’s goals” (Berkman, Davis, & McCormack, 2010, p. 17). As one study states on this point, “the constituent dimensions of health literacy remain disputed and the attempts to operationalize the concept vary widely in scope, method and quality” (Sorensen et al., 2012, p. 2). The 2003 National Literacy Assessment needs to be repeated, especially with the rise and substantial impact of social media on all aspects of American culture and communication. The literature has shown that the permeating challenges of health literacy include its depth, breadth, and fluidity; being a function not just of traditional communication-oriented skills (written and verbal communication) but also the ever-changing inputs of social context and communication mediums.

Likewise, CAHPS needs to be updated to account for the influences of social media and changing technology as well. Similar to the conclusions on health literacy, the literature on patient experience casts the conclusion that there remains a lack of consensus on how experience is measured. As LaVela and Gallan state in their 2014 article, “Patient experience seeks to represent a unique encompassing dimension that is challenging to measure because it is a complex, ambiguous concept that lacks a common definition” (LaVela & Gallan, 2014, p. 34). The way we consume and process information in all forums today is dramatically different than it was even just a decade ago. The way industry, government, and regulators measure these concepts must adapt accordingly if the information gathered is to remain relevant and insightful for policy leaders, organizational decision-makers, and patients.

Finally, both health literacy and patient experience are not easy. Improvement in these areas, especially sustained improvement, has been shown throughout the literature to be elusive for many. Similarly, the literature in both arenas has shown improved health literacy and patient experience to have significant positive impacts on patient outcomes and other quality of care metrics. Bottom line, if an organization can figure these out, their patients will greatly benefit from improved health status and improved morale. Because health literacy challenges are so widespread, concentrating efforts on health literacy improvement will likely yield a number of measurable benefits for the organization that undertakes the commitment; including better ratings of patient experience and improved scoring in the Value Based Purchasing program. In turn, achieving sustained improvement of the patient experience can lead to the four best possible results in health service delivery: improved clinical outcomes, healthier financial outcomes, increased customer/consumer loyalty and enhanced community reputation (Wolf, 2016).

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